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Encountering Christ Through the Passion of HIV: an Inquiry into the Theological Meaning of HIV in the Church

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Encountering Christ through the Passion of HIV

**An inquiry into the theological meaning of HIV in
the Church**

Vincent Manning
St. Marys University, Twickenham

A thesis submitted to the University of Surrey for the award
of Doctor of Philosophy

June 2019

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14th June 2019

University of Surrey
Thesis submitted for the degree of Doctor of Philosophy
By Vincent Manning (St. Marys University, Twickenham)
June 2019

Abstract

Encountering Christ through the Passion of HIV: An inquiry into the theological meaning of HIV in the Church

This thesis argues that living with HIV today can be understood theologically as a type of 'passion experience'. Ten Christian women and men diagnosed with HIV in England have been interviewed. A close reading of their accounts of Christian life and faith will reveal similarities between their experience and that of Jesus and His disciples during the time from Gethsemane to the Resurrection. I will argue that living with HIV can be interpreted as a type of privileged encounter with Christ in His Passion.

The study is structured as a series of encounters with HIV in two parts. In each chapter, in distinct ways, aspects of the phenomenon of HIV are examined. Part I justifies this research, explains why it is needed, and sets out in detail the methodological approach I have taken so that fresh insights and a deeper understanding of what it means to say that 'the body of Christ is living with HIV today' is revealed. I argue that the situation of people living with HIV today is misunderstood. Consequently, their pastoral and spiritual needs are not addressed within the Church. This situation arises because most people think that an HIV diagnosis is no longer as problematic as it once was. I will argue for the importance of memory and set out the historical context of HIV and Aids in both society (chapter one) and in the Church (chapter two) and provide a description of the contemporary reality of living with HIV in this country today. To understand the experience of living with HIV as described by my principle subjects, it is necessary to remember the disruptive force of HIV in both society and the Church and have an accurate description of the present reality. As I will argue, understanding or misunderstanding the past directly effects how HIV and those who live with HIV are encountered.

My interviews with eight theologian-practitioners in chapter four will map the theological terrain of HIV. I argue that the significance of HIV is yet to be fully explored and remains potentially disruptive both within the Church and for academic theology. The value of personal encounters with HIV for these theologians will be evidenced. Having contextualised this study socially and theologically, the reader will encounter my principle research participants in their own words in chapter five. I will argue that what HIV means theologically cannot be apprehended with-out vulnerable encounter.

Part II presents the main theological argument. An HIV diagnosis will be revealed as a type of gethsemane experience. I will show how my participants have undergone the passion of HIV and the scandal of the cross, and how they have made faith-sense of HIV. I argue that healing and strengthening are needed to carry the cross of HIV as disciples of Christ. Finally, I will argue that insofar as these sisters and brothers remain excluded and neglected, the whole body of Christ is diminished.

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Acronyms, specialist references and terms

ACT UP – AIDS Coalition to Unleash Power

AIDS & Aids - Acquired Immune Deficiency Syndrome

ACET – AIDS Care Education and Training

APPG - All Party Parliamentary Group

ARV - Anti Retro Viral (HIV medicine)

BAME - Black Asian and Minority Ethnic

BBC - British Broadcasting Company

BHIVA – British HIV Association

BIAPT – British and Irish Association for Practical Theology

Cafod – Catholic Association for Overseas Development

CAL - Catholic AIDS Link

CAPS - Catholics for AIDS Prevention and Support

CATHAM - Westminster Diocese (Roman Catholic) HIV and Aids Ministry

CCC – Catechism of the Catholic Church

CD4 - White blood cells that play an important role in the immune system. The CD4 cell count is routinely undertaken in clinical care and gives an indication of the health of the immune system

CDF – Congregation for the Doctrine of Faith

CI - Caritas Internationalis – A confederation of 165 Catholic relief, development and social service organisations operating in over 200 countries and territories worldwide

CJD - Creutzfeldt-Jakob disease

CMV - Cytomegalovirus - an Aids defining infection that leads to blindness

CSB – Catholic Study Bible

EAA – The Ecumenical Advocacy Alliance

EG - Pope Francis, 2013. *Evangelii Gaudium. The Joy of the Gospel*. London: CTS.

EUROPACH - ‘Disentangling European HIV/AIDS Policies: Activism, Citizenship & Health’

FPA - The Family Planning Association

Frontliners – Support group for people with Aids

GMHC – Gay Men’s Health Crisis New York

HIV - Human Immunodeficiency Virus

IPA - Interpretative Phenomenological Analysis

ITN - Independent Television News

Kaposi's's Sarcoma – a normally rare Aids defining cancer

KFF – Henry J. Kaiser Family foundation

KJV – King James Version

LEAT - London Ecumenical AIDS Trust

LGBT – Lesbian, Gay, Bisexual and Transgender

LGCM – Lesbian and Gay Christian Movement

NAM - National AIDS Manual

NAT - National AIDS Trust

NHS – National Health Service

NICE - National Institute for Clinical Excellence

NIV – New International Version

NJB – New Jerusalem Bible

NLT – New Living Translation

NRSV – New Revised Standard Version

PCA – Carl Rogers' Person Centred Approach

PEPFAR - The President's Emergency Plan for AIDS Relief

PHE - Public Health England

PrEP – Pre Exposure Prophylactic (preventative HIV treatment – commonly oral tablets)

Positive Catholics – Faith based HIV Peer Support network

Positive Faith – CAPS' Educational HIV Prevention Resources and short Films Website

PPC – Positive Parenting and Children Charity

Quest – Support network for Catholic LGBT people

SFAF - San Francisco AIDS Foundation

TAR - Theological Action Research

UNAIDS – United Nations international Aids agency

USCCB – United States Catholic Conference of Bishops

VD – Venereal disease

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This study could not have been undertaken without the courageous participation of those Christians living with HIV who agreed to be interviewed for this research. I hope that my interviewees will feel that I have treated their stories with care and respect. I wish to thank each person for their willingness and honesty. Your faith may serve to encourage and strengthen others.

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INTRODUCTION

Introduction

The purpose of this study is to analyse the phenomenon of HIV within the Church¹ in the UK today, and to uncover theological meaning within that lived experience. To my knowledge this is the first study which attempts to answer the question ‘what does it mean when we say that the body of Christ is living with HIV in this country today?’² In this introduction, I will outline the premise for this research and the main themes within this thesis, and point towards the issues raised and the arguments I make in the study. This chapter also introduces the reader to the way in which I intend to present this study as a type of encounter with the phenomenon of HIV and with the subjects of this study who embody HIV theologically. I begin with an overview of the structure of my research as presented here.

Following this introductory chapter, Part I of this thesis begins with the broader historical and contemporary context for this study. In chapter one I will consider the first days of the epidemic and responses within society, and contrast the reality today with the situation in the past. Chapter two takes a similar historical view of Christian pastoral and theological responses, and describes the current reality. My argument proceeds through chapter three which explains my methodological approach in detail. Chapters four and five are accounts of interviews conducted with theologian practitioners and people living with HIV respectively and describe the rich data and questions generated as I proceeded with my research. In these ways Part I, as a whole, contextualises this study, presenting an overview of the terrain of study and explaining how I have arrived at the argument that I make in Part II. Taken together the five chapters following this introduction offer a wide lens through which

¹In this thesis when I use church or Church I mean to include all Christians and will specify whenever I am referring to a particular Church i.e. the Roman Catholic or the Anglican Church. When using a small ‘c’ the description may be of a small group of Christians gathered together locally, or to the Christian church globally. When I intend to emphasise and specifically include aspects of the church as an institution, I will use a capital ‘C’. This is a guide rather than a strict rule, the ecclesiological meaning of the use of the word Church and church should be understandable within the context of a given sentence.

² By ‘this country’ I mean specifically England and Wales as part of the United Kingdom but exclude Scotland and Northern Ireland. This reflects the distinct juridical-hierarchical regions of the Roman Catholic Church, and my choice to address the situation of the Church in England and Wales. Historical, epidemiological, cultural and pastoral conditions may vary significantly within the Scottish or Irish context. Similarly, when referring to the UK I am referring primarily to England and Wales, although at times the whole of the UK is included e.g. when UK statistics are quoted in chapter one.

the complexity of HIV as a site of theological inquiry will be revealed and viewed, before a more narrowly focused theological argument is presented in Part II.

In this introduction I begin with an explanation of my own relatedness to the situation, my personal motives for commencing this research, why I think it is needed and how my experience has shaped what this study aims to accomplish. As I will explain in detail in chapter three, reflexivity is important for the validity of this study. This requires a degree of personal honesty that may not be necessary in other research. Throughout I give priority to the experience of others, it is their voices that provide authority for the arguments that I make. It is important therefore that I declare my own motives and biases so that the reader may come to an informed opinion and understanding of what is presented. As I am attempting to mediate the experience of my interviewee-subjects for the reader, as a type of encounter with these different people, it is important that I am clear about what belongs to me, whether experience, opinion, belief or feeling – and what belongs to others. I will describe my pastoral ministry and explain how that influences the aims of this study, namely: that it is informative for any reader wishing to reflect theologically upon what it means to live with HIV today; and that it is pastorally helpful for any person living with HIV.

After declaring my personal situated-ness I will describe the ways in which this study can be understood as theology. I will explain why this research is presented as a type of necessary encounter with HIV, and the importance of the body as a theological site. With reference to three historical events, I will show how the theological phrase ‘the body of Christ living with HIV’ is most powerfully understood when mediated through the embodied presence of people who have been diagnosed with HIV, and I will argue that HIV has been forgotten about, in large part because of a lack of embodied encounter. I will make reference to what can be expected in further chapters, summarise the aims and limitations of this study, and provide the reader with a brief guide to the chapters that follow.

Personal encounters with HIV in the body of Christ

My first encounter with HIV and Aids³ was in Keller’s Bar, at the end of Christopher Street in Greenwich Village, New York City, when I was 19 years of age. I had a habit then, of placing

³ Throughout I will use ‘Aids’ rather than ‘AIDS’ unless quoting others who have used the latter. From the late eighties it has been debated whether to use the capitalised notation or not. The objection has been that in

a dollar bill in my empty beer mug as a signal to Barry, the bartender, that I was ready for a refill. “You don’t know where that dollar bill has been” a friend warned me. “You have no idea how many hands it has passed through or how many pockets it has been in. Haven’t you heard? There is this mysterious disease going round killing gay men, and no-one knows how you catch it?” Well I hadn’t heard. I recall dismissing his comment, although I did stop placing dollar bills in beer mugs. His point about general hygiene was a good one. That was early 1982.

In 1984 I returned to live in Bristol in the UK. The significance of the warning began to sink in when friends of mine began to fall ill. The fear and anxiety that accompanied these first vicarious encounters with HIV extended well beyond the person in question. With each reported diagnosis or suspicion of sickness Aids stepped closer. Each new story of Aids was at once a personal tragedy, and an imminent threat to us as individuals and as a community of friends. No-one felt safe, but no-one really knew what it was that we were being threatened by. We had yet to realise that these first cautionary tales heralded a pandemic of global proportions. The story of Aids was just beginning.

With time, advances in scientific understanding made us more aware of the causes of infection and the condition called Aids.⁴ Public awareness was impacted by reports in the media. I recall Rock Hudson’s death from Aids being broadcast on the BBC in 1985. Pictures of him looking weak and emaciated seared into the public imagination the skeletal image that would define Aids. His fame and the deaths of other celebrities ensured that Aids intruded shockingly into ordinary people’s consciousness.⁵ It would be a mistake, however, to think that the public imagination was well informed. Despite major public health campaigns in the UK, ignorance and fear of Aids and HIV persisted. Prejudicial attitudes resulted in numerous unkind, unjust, and discriminatory actions in families, schools,

capitals ‘AIDS’ conveys an alarmist quality which increases the fear associated with the disease and therefore adds to HIV stigma. I also argue that ‘Aids’ has become a *de facto* word commonly understood linguistically and need no longer be capitalised.

⁴ It was not until 1986 that the name for the virus that causes Aids was agreed as HIV (Grmek, 1990, p.70), although it was known since 1985 that a virus was the cause of infection.

⁵ For example amongst others, in the UK the popular comedian Kenny Everett, film maker Derek Jarman and the international rock-star Freddy Mercury all died of Aids in the early 1990s.

churches, medical establishments, funeral parlours, and workplaces that marginalised and excluded people infected with HIV or diagnosed with Aids.⁶

HIV and Aids in the UK was defined in the early years by fear, shaped at first by the particular story of Aids as it unfolded within the gay communities of New York and San Francisco. Randy Shilts (1988, p.1)⁷ begins his account with a quote from the Book of Revelation: "And I looked, and behold a pale horse: and his name that sat on him was Death, and hell followed with him." This apocalyptic tone captures the shocking realisation that began to emerge. Something truly devastating, death dealing and terrifying was upon us. Something bigger and uglier, than anything most of us had seen or experienced before. And this ugliness appeared in the bodies of friends that we knew and loved. We could touch it, and it had touched us.

It was a time and place of heightened vulnerability especially within the gay community. In the years that followed, confronted with the emerging reality of Aids, the sense of defencelessness became gradually more present, more real. Each reminder of Aids was a reminder to me that I too was vulnerable. I had to face the reality: each person with Aids was an embodied reflection of my own vulnerability.

I am more conscious of these things now. I could not have admitted such things to myself then. I do remember feeling ashamed by my reluctance to visit those who were sick, and the sense of exhaustion that always followed those visits to specialist wards set apart from the main hospital, in isolation, often outside 'the walls' of society.⁸ My own resistance to those encounters, my urge to flee the scene of Aids, experienced then as bodily discomfort, noticed rather than consciously articulated, disturbed me. Central to my understanding of

⁶ Accounts of prejudice and discrimination are common in the literature. See Weeks, 1993, p.26; Kubler-Ross, 1987, especially pp. 107-137 which detail newspaper correspondence in regard to the controversy over provision of a centre to care for children infected and affected by HIV and Aids in a rural American community; Goss and Adam-Smith, 1995, in Aggleton et al., 1995, for a discussion on workplace attitudes; Garfield, 1995, pp. 172-184, regarding employment, insurance, immigration; Cosstick, 1987, pp. 47-50; Richardson and Bolle, 1992, pp. 88-94; and Cadwallader, 1992, pp. 27-54, for first person accounts.

⁷ Shilts died in 1994. He was a journalist and author of 'And the Band Played On', a best-selling historic account of the emergence of Aids in the USA. The quote is from Revelation 6:8.

⁸ For example, in the 1980s and 1990s in-patient care for people diagnosed with Aids in the Bristol area was provided at Hambrook Hospital on the outskirts of the city. At the time I recall that Hambrook hospital had a reputation based upon previously being the place of quarantine for people with contagious respiratory diseases.

Christianity then and now are the corporal works of mercy.⁹ Christianity is about identification with and solidarity alongside those on the margins of society. The Gospels show that Jesus identified himself with the outcasts, the rejected and despised ones in His time. To be His disciple is to do the same. How could I call myself Christian and yet be so resistant to identifying myself as belonging, in any way, with the outcasts of my time?

Even being seen to associate with someone thought to have Aids challenged my faith. In my understanding, the stigma associated with Aids in society put those living with Aids in the place of Jesus prior to his crucifixion. My reluctance to be associated with them put me in the place of Peter, hiding in the shadows, fearful of being found out. Afraid that I might be called 'one of them' (Mk. 14:69-70).

In his book about caring for people living with Aids Bill Kirkpatrick (1927-2018)¹⁰ says that "in order to help people, we need to be psychologically comfortable with our own suffering; our own fears of contagion and infection; our own sexuality (a great problem for many Christians) and our own mortality" (Kirkpatrick, 1993, p.4).

As a young man I was even less psychologically comfortable with my own suffering, fears and sexuality than I am today. I am not so sure that in order to help others today we need to be as well-adjusted as this quote implies. However, the clues are here as to why as a young man I felt such resistance to my encounters with Aids. In theory I believed that every person suffering with Aids "is Jesus in painful disguise, indeed is all of us in painful disguise" (Kirkpatrick, 1993, pp. 3-4). In practice, beholding this Jesus in painful disguise was much more difficult, because as Kirkpatrick suggested to do so meant confronting my own disguised pain.

⁹ The corporal works of mercy are: visiting those in prison; giving shelter to the homeless; feeding the hungry; giving drink to those who are thirsty; burying the dead; visiting the sick; and clothing the naked (Keenan, 2005).

¹⁰ Kirkpatrick was a Church of England priest. He was an early Aids activist in this country and author of 'AIDS: Sharing the Pain' one of the first works of pastoral theology, published in England in 1988. Krystyna Fuchs who was a volunteer at THT in the mid-eighties and a founding member of CAL recalls how Bill Kirkpatrick was "running around conducting funerals and burying the dead, exhausting himself when other clergy refused to help." (Conversation 25th May 2019). As this thesis provides an original historical account of ecclesial and pastoral responses to HIV and Aids in this country I include birth and death dates for those prominent activists and theologians who I consider important and have since died, both to honour their memory and to assist any researcher interested in constructing a more comprehensive historical account elsewhere. I will say more about the importance of memory and remembering in chapter six.

My own unavoidable experience that began in the early eighties has brought me to this place, and this particular attempt to make theological sense of a wider reality. I do not see it as a journey of personal choice as much as a story of forced encounter. Of course, I have made decisions throughout this journey, as in those earliest days when I decided to visit some people who were dying of Aids despite my fears. My shallow understanding was at least sufficient to compel me to do on some occasions, what I was anxious to avoid most of the time. Yet my encounter with HIV in that first decade was one of reacting to events, being led, rather than anything more pro-active. I have been a reluctant participant.

Pastoral ministry

By 1990 I was actively involved with the charity Catholic AIDS Link (CAL). I wrote articles published anonymously by CAL¹¹ and became a coordinating group member, often leading days of HIV and faith training for parishioners and clergy throughout England. CAL closed in 1999 for reasons that will be discussed in chapter two. In 2004 I was asked to facilitate a workshop at a conference held at Vaughan House, Westminster, London, organised jointly by the Westminster Roman Catholic HIV and Aids Ministry (CATHAM)¹² and Catholics for AIDS Prevention and Support (CAPS), the successor charity to CAL established in January 2003. The aim of the conference was to take stock of the situation in regard to HIV ministry in England and Wales and to consider what the priorities going forward might be. The workshop that I led invited any person present living directly with HIV who wished to, into discussion about their own pastoral needs. The majority of the people who took part were African, and mostly from Christian traditions other than Roman Catholic. I remember one woman from a Pentecostal church explained that even though this was a conference clearly organised by the Roman Catholic Church she had seen the words Christian and HIV in the publicity, and “I just had to come.” She expressed a shared feeling in that group that the spiritual and pastoral needs of Christians living with HIV in England were neglected. For an hour people shared their stories with each other. At the close of the workshop everyone

¹¹‘Suffering and Hope’ was published in CAL News, no. 7, March 1991. My 10 point guide for priests was published in CAL News, no. 8, July 1991. Both articles were reproduced in CAL, 1995a. I formally became a member of CAL Coordinating group in 1991.

¹² Catherine McErlean a Sister of Charity of St. Vincent de Paul held the only salaried post of any Roman Catholic Diocese within England and Wales, part-time, specifically dedicated to the pastoral support of people living with HIV and Aids. She resigned in 2008 and the post has not been re-advertised.

expressed a sense of great relief at having been able to speak openly about their faith and living with HIV with others who understood them. To conclude, I asked them directly ‘what do you want from the Church?’ In response they stated a need for well informed and sensitive pastors in whom they could confide and secondly that further similar opportunities be provided so that they might gather as Christians living with HIV in a spirit of openness and honesty for prayer and sharing. It did not seem to me to be very much to ask. The first request would require a strategy of training and education. In response to the second, I agreed, along with CAPS trustee Stephen Portlock SJ (1949-2016),¹³ to facilitate a monthly gathering for Christians living with HIV. According to our informants sensitive trained clergy were very few and far between, at least Stephen and I, having both been diagnosed with HIV, could attempt to organise opportunities for the Christian fellowship that these people so clearly desired and needed.

The first meeting was held one afternoon in the basement hall of the Church of Our Lady and St. Gregory, Warwick St., London on 25th September 2004. In total seven people attended.¹⁴ I was reluctant to make too great a commitment. My own health had been very poor in the previous two years, I was without a stable place to live, and recently unemployed. I agreed to lead the group for a year. We named this small ‘fellowship of the weak’¹⁵ ‘Positive Catholics’ whilst remaining determinedly ecumenical and open to any person living with HIV who wished to join us. We also agreed, contrary to convention within the secular HIV sector, to be inclusive of men and women, gay and straight, resisting the usual separation into groups for gay men, or Africans, or women and so on. As this group was formed because Christians living with HIV felt excluded in the churches, we agreed to be as inclusive and welcoming as possible – in some small way ‘to be the change’ that we wished to see in the Church. Our first mark of shared identity was not that of an HIV diagnosis, but baptism, which made us sisters and brothers, one body in Christ.¹⁶

¹³ Stephen Portlock was a member of the Society of Jesus at the time. He later unwillingly left the Society, in part because his health was considered too poor to allow him to complete his training and proceed to ordination. However, he remained close to the Society of Jesus and always considered himself a Jesuit. He continued to facilitate the Positive Catholics groups after leaving the Society of Jesus hosting meetings at his home in Vauxhall, London until his health declined further in 2014.

¹⁴ From CAPS records and notes taken at the time.

¹⁵ I borrow the phrase from Henri Nouwen, 2006, p.48.

¹⁶ Gal. 3:27-28; 1 Cor. 3:23.

Since these small beginnings, CAPS has grown as a charity and the Positive Catholics peer support ministry continues. Since 2004 several hundred individual Christians living with HIV have attended peer support meetings to share their experience, pray together, and support one another practically and pastorally. Two Positive Catholics groups meet each month in London and Manchester, and each year weekend retreats for individuals and families living with HIV take place, where bonds of fellowship can be strengthened. My initial commitment got extended somewhat. I have been Chair of CAPS since 2008 and continue as a leader in this ministry.¹⁷ For me then, in the first instance, HIV and Aids is personal.

Motivation and aims of this study

A principle motivation for commencing this research has been my frustration that in terms of Christians living with HIV feeling accepted in Church, the situation has not changed much. History repeats itself. The members of Positive Catholics, especially those who are recently diagnosed, from all Christian denominations, consistently speak of their exclusion from and their keeping of secrets within all the churches. The impact of HIV stigma for these Christians remains, in effect, as powerful as the stigma that existed in previous years. I will argue, particularly in chapter six, that an accurate memory of the past is necessary, not least for a fuller appreciation of the reasons why stigma stubbornly persists. Understanding the past sheds light on the present.

However, in the course of my research I discovered that an historical account of the Church's responses to HIV and Aids in this country has not been written. Therefore, beginning below with an account of two important theological conferences, and continuing in greater detail in chapter two, I make an original contribution to public knowledge with a summary of the theological and pastoral responses to HIV. I present the first historical account of HIV in the Church in this country in a single study.

Chapters one and two set out the historical and contemporary context which is necessary for understanding HIV as a lived experience today. Together they provide important

¹⁷ CAPS' charitable work is not restricted to the Positive Catholics ministry. CAPS also undertakes education and prevention work within Church and the HIV and medical sectors. However, trustees have prioritised the Positive Catholics and peer support ministry as the essential aspect of CAPS work. The charity has grown considerably since 2004, reliant wholly on the commitment of volunteers. At time of writing CAPS has never had any salaried employees. For information regarding CAPS' current activity and copies of annual reports see CAPS website listed in bibliography.

background information to support the argument in Part II of this study that living with HIV can be understood as a type of 'Passion experience'. In chapter two I will argue that Christian responses to the reality of HIV in our midst have followed a kind of arc from a low point of no responses, through fuller engagement, and then back again to a disengaged stance in relation to HIV. I will show how this has effectively rendered people living with HIV silent and invisible. I will argue that the lack of visibility of Christians diagnosed with HIV in our Church today means that honest encounters between Christians, members of one body, do not actually take place. This has two consequences. First, the need for support and understanding from a community of faith is not available to people living with HIV. Second, insofar as any Christian remains hidden and secretive within a faith community, to that extent, the wider body is deprived of their real presence and fullest participation in the life of the church. This study then, has originated in my conviction that not only do our sisters and brothers living with HIV have something of value to share with the wider Church, but that their voices deserve to be heard; as a matter of human dignity and justice they deserve a basic recognition which they are presently denied.

A second motivation related to my role in CAPS has to do with the public and ecclesial credibility of CAPS as a Christian ministry that advocates for the needs of people living with HIV in this country today. Any type of Christian ministry requires funding and support and that is difficult to obtain when the actual needs of those for whom CAPS exists are unrecognised. It has been my hope that in the process of research, within the Church and academia, a greater awareness of people's pastoral needs will become known. Through writing, attending academic conferences and presenting short papers, challenging the prevailing idea that 'Aids is over' and that the needs of people are met within the voluntary and medical sectors, I think this study has contributed in a small way already, to a greater awareness within the Church locally, and a fuller appreciation of what the volunteers in CAPS ministry, most of whom are also living with HIV, are doing in acts of Christian service for others, on behalf of the wider Church (Cosstick, 2013, 2017; Falcone and Manning, 2015; Manning, 2011, 2014, 2014a, 2015, 2016, 2017, 2018; McManus, 2017, 2017a; Morris and Manning, 2017; Stewart, 2017; Thornhill and Manning, 2010; Williams, 2017). I shall return to my argument that the phenomenon and meaning of HIV and Aids in society today is misunderstood in chapter six. Within academia similarly, I have been motivated to re-

establish HIV as a site of meaningful theological inquiry. Whether or not that case has been made is for others to judge. Whether my research and this thesis stimulate further theological inquiry or raise new questions remains to be seen.

The main aim of this study, therefore, is to analyse the phenomenon of HIV in the Church in this country today. I make the case that HIV remains an important site for ongoing theological reflection within academia and the Church and deepen understanding by bringing to public view that which is hidden. The arguments that I make and the evidence presented in Part I will set the scene for the theological argument in Part II.

Methodologically my argument proceeds via a series of encounters which I present in each chapter. Throughout, the reader will encounter people who have lived and died with HIV and Aids; theologians who have reflected upon HIV as a sign of the times; and clergy, lay Christians and activists who have responded in various ways. Below, I will say more about the importance of experience and encounter for this study.

The central theological argument of this thesis in Part II is that the experience of diagnosis and the challenges of living with HIV can be understood as a type of 'Passion experience'. Revisiting the historical context and background of HIV as a phenomenon in British society with the stories my interviewees tell in chapters four and five, will show that the meaning of HIV is often only understood through embodied encounters – 'graced encounters' - with the Christ who is met in the lives of those who have undergone the trials and tests of HIV. In part II my argument is that these Christians living with HIV can both identify with and be identified as the Christ who first suffered, died and is risen, through His Passion experience. Seen through the eyes of faith I mean to present their experience, as encounters with Christ.

Whilst this study is primarily intended to contribute to academic knowledge, a subsidiary aim is that this research has pastoral relevance for any person living with or closely affected by HIV. Given the lack of pastorally relevant theology,¹⁸ I have kept in mind throughout, the Christian person diagnosed with HIV. In Part II especially, where I argue that the experience of living with HIV can be understood theologically as a type of privileged encounter with

¹⁸ I found no published theology that might be considered pastorally useful and directly addresses the situation of people living with HIV in a Western European context since Bassett et al., 2007.

Christ, I intend this work to be of some encouragement in faith for any such person. I am convinced that an interpretation of painful experience through the lens of the Cross and Passion has the potential to respond to suffering in its depths and contribute to the alleviation of that suffering. It may be healing or liberating if even a slight shift in the way someone views his or her experience occurs. "It might offer the courage to venture a first tentative step out of the malaise of isolation that suffering engenders." (Thornton, 2002, p.23).¹⁹

Theological content, approach and boundaries of this study

It is not a simple matter to define this study as fitting narrowly within any one branch of theology. I did not begin my research with any clearly defined theological category within which this inquiry could be located; neither have I rigidly adopted a particular theological method, as will be clear in chapter three. However, I have drawn upon pastoral and practical theologies, and because people living with HIV today remain an oppressed and marginalised group in various ways, as I will argue throughout, liberationist theologies are important for this thesis.

This study is Practical Theology insofar as I present arguments about the meaning(s) of faith within a given situation (Farley, 1987; Swinton and Mowat, 2009, pp. 12-16). Practical theology is always contextual (Schreiter, 2010).²⁰ Part I of this thesis aims to situate my research contextually in different ways. In chapters one and two this study is contextualised historically, sociologically and ecclesiologically. In my interviews with theologians in chapter four the context of the wider theological community is discussed, and chapter five provides the reader with additional detail for each of my principal subjects, which serves to contextualise the later passion experiences at the heart of this thesis.

The practices of the Church are central for practical and pastoral theology (Ballard and Pritchard, 2006, p.18) and will be critically considered in chapter two where I examine pastoral and theological responses to HIV; and throughout this study whenever implicitly or

¹⁹ Sharon Thornton is Professor Emeritus in pastoral theology at Andover Newton Theological School in Massachusetts. I found *Broken Yet Beloved: A Pastoral Theology of the Cross* (2002) particularly relevant for this study.

²⁰ John Swinton is Professor in practical theology and pastoral care, and Harriet Mowat is an honorary Research Fellow, both at Aberdeen university. I found their *Practical Theology and Qualitative Research* (2009) especially useful for this study.

explicitly the practices of the Church are called into question (Cameron et al. 2010, pp. 22-24), for example, as below, in my critique of three historic events which illustrate the importance of embodied encounter.²¹

Practical Theology is often concerned with what the members of a community of faith do – and how the body of Christ is actualised in society (Campbell, 1990, pp. 84-86). By definition this inquiry into the meaning of HIV ‘in the body of Christ’ has an ecclesiological dimension. However, early in the research process I had a ‘hunch’ that to define the aims of this research in terms of the pastoral practices of the whole Church, or a particular parish or local community of faith, would be limiting in terms of the process of what might be discovered, and inhibit my participant-subjects in terms of what they chose to share. My approach has been to patiently wait for the theology to arise from the various encounters that I have had throughout the period and process of research. My method may be understood as a practical theology through encounter. I will justify this approach and explain how I have applied it more fully in chapters three, four and five.

Consequently, the theology that has emerged and is presented here is distinctive when compared with the existing theological literature. For example, much of the published literature considers the role of the churches in matters of HIV prevention. Given the scale of the pandemic as a global health emergency and controversies relating to HIV education and prevention (condom use being the most obvious example), important contributions have been made previously (Keenan, 1999, 2000; Owens, 2000; Green, 2006; Paterson, 2009b; Casale et al. 2010; Sutton and Parks, 2013; Dowers, 2018).²² This study does not focus on any one particular doctrine or area of Christian theology, for example sexual ethics (Kelly, 1998; Basset et al. 2007; Chitando and Njoroge, 2015). I make no attempt to critically appraise the Catholic theology of marriage as Reimer-Barry (2011) has or examine the liturgical practices of the Church (LeClerq, 2010, pp. 119-162), or provide a template for

²¹ Paul Ballard is Emeritus Professor in the School of Religious and Theological Studies, Cardiff University. John Pritchard was Director of Pastoral Studies at Cranmer Hall, Durham and is a retired Anglican bishop. Dr. Helen Cameron founded the Oxford Centre for Ecclesiology and Practical Theology. She is currently visiting Fellow, Centre for Christianity and Culture, Regent's Park College, Oxford & Head of The Salvation Army Public Affairs.

²² Professor James Keenan, S.J., is a moral theologian and Director of The Jesuit Institute at Boston College. He has written extensively on HIV. He supervised the doctoral research for Vincent LeClerq's *Blessed are the vulnerable* (2010) which is an important recent work and an example of theology written from the perspective of people most directly impacted by HIV.

Christian action (Parry, 2008; 2014). Issues of sexual morality, HIV education and prevention and the role of the Church, matters of ecclesiology, the pandemic as a global phenomenon and issues of social justice will all be referred to, directly and indirectly throughout this thesis. To assist the reader, important published theology, as well as social science sources, will be highlighted within the body of my text as I have done here, or in footnotes. Paying attention to important literature as my argument proceeds, in order to illustrate specific points that construct my argument, replaces the more traditional inclusion of a thesis chapter dedicated to a 'literature review'. I trust this is a more relevant way in which to utilise the contributions of other scholars.²³ However, as I will explain and justify in more detail in chapters three, four and five, a narrow consideration of a particular doctrine or a focus on any single theologian's work is not an aim of this study.

I will identify pastoral deficiencies within the Church, and argue that there is a lack of real communion in practice. Chapters two, four and five will leave the reader in no doubt that HIV has exposed and continues to reveal fault-lines of division and disunity within the one body of Christ. These divisions are not merely doctrinal arguments; they are signs of and arise from habitual attitudes, anxieties and practices within ecclesial culture and result practically in choices being made whether to tend or not to people in need; to speak up or keep silent about matters of sex and sexuality; to direct our theological attention and pastoral resources in one way rather than another; to include some people and exclude others, deliberately or simply because they remain hidden within the community called Church, and so on. In other places, notably in chapter nine, I reveal alternative expressions and practices of faith within a part of the church, namely how the communion of faith is enacted between and amongst Christians living with HIV.

In these ways and within these limits this study is Practical Theology. An interdisciplinary approach and the use of qualitative methods and reference to social scientific research is a further way in which this study is practical-theological (Pattison, 1986).²⁴ Above all the priority given to experience throughout this thesis, whilst not sufficient alone to arrive at

²³ Literature is reviewed through Part I of this thesis. Chapter four includes detail of the review of theology undertaken during research interviews with theologians.

²⁴ Prof. Stephen Pattison is a leading British Practical theologian currently at Department of Theology and Religion at the University of Birmingham.

theological insights, is grounded in my understanding that the Christian faith is living, relational, incarnational and embodied, before it is doctrinal or a mere set of propositions or beliefs to be intellectually debated (EG 7).²⁵ I argue that the significance of experience within an oppressive social-ecclesial context, places this study theologically within the field of Pastoral, Practical and Liberationist Theologies (Woodward and Pattison, 2007, pp. 2-19; Sweeney, Simmonds and Lonsdale, 2010, p.2; Beaudoin and Hinze, 2014).²⁶

As a Christian belonging to the Roman Catholic Church I have drawn upon a number of Catholic theological sources, and that influence will be evident throughout this study. The Christians living with HIV interviewed for this study are also all people who have been formed in their faith within the context of the Catholic Church. Nevertheless I think that the theological, ecclesiological, moral and personal issues and challenges that are raised throughout this thesis will have application and relevance across all Christian traditions. Therefore I have chosen to address the question as far as possible in ecumenical perspective. When I refer to the church in this study I mean to include Christians, lay and ordained from all traditions.²⁷ I intend this study to be understood by and relevant for any reader with an interest in Christian theology and HIV, and that the arguments I make and the evidence I provide will be relevant across Christian denominational lines.

Underground theology

In my research interview with theologian Julie Clague, I explained that I felt this study was needed because I knew that Christian practices and expressions of solidarity were taking place within the church in this country about which most people are quite unaware. I happened upon the phrase, 'underground theology' as a way to describe this situation. Above ground, the Church is visible and actualised through buildings and institutions, in charitable works and political activity, through Church leaders in the media, in Parliament and every local parish, and lately through the scandals of clerical sexual abuse. Whatever a

²⁵ Pope Francis, 2013. *Evangelii Gaudium. The Joy of the Gospel*.

²⁶ James Woodward is a practical theologian and has been Principal of Sarum College since October 2015. His *Embracing the chaos* (1991) is an important early collection of theological essays in response to Aids. Sweeney et al. 2010 make an important contribution to the development of practical theology in Roman Catholic perspective. Sweeney also co-authored *Talking About God in Practice* (Cameron et al. 2010) which offers an original practical theological methodology called 'Theological Action Research' (TAR).

²⁷ See footnote 1.

person may think, rightly or wrongly about the Church, that it exists in the midst of society is evident. In the Church the members are aware of so much that happens in the name of Christianity, for both good and ill. The views of the Pope and the Archbishop of Canterbury will be heard around the world, and so on. However, there are members of the same body of Christ who comprise a hidden community, underground as it were, and out of sight, who are also church. What I present in this study, both in terms of my approach to 'doing theology' described principally in chapters three, four and five, and the faith experience, spirituality and theological arguments I put forward in Part II, come from the people who are at the heart of this study. It is not only individual faith experience that will be presented here, I will bring to light some of the ways that these Christians living with HIV practice compassion, offer one another fellowship and worship together as their way of being the body of Christ, in communion with one another in an underground place, hardly known by those who exist on the surface. This underground theology and the practices of this fellowship of the weak will be referred to in this study.

Experience, encounter and the body of Christ living with HIV

The importance of lived experience is accepted as a theological starting point, especially when considering oppressive situations and the lives of marginalised people (Kelly, 1998, p. 81; Owens, 2000, p.165; Smith and McDonagh, 2003, p.9; Schneiders, 2004, p.16; Orobator, 2005, p.122; LeClerq, 2010, p.35; Mulligan, 2011).²⁸ This turn means more than just a respectful attitude to others' experience, or taking the social and political situation in which they live into account. It includes these considerations and begins with listening and attentiveness. However, the locus of experience is important because it is also the locus for interpersonal encounter. Paying attention to the experience of others has the potential to be a graced encounter. This may seem obvious, but I think it worth stating explicitly.

The first time that HIV and Aids was spoken of theologically as being within the body of Christ, it caused controversy. As I will explain in the next chapter where I outline historical reactions to the pandemic, the response of the churches was slow in this country. To illustrate why I regard experience and encounter as theologically central for this study I

²⁸Agbonkhianmeghe Orobator SJ is the President of the Conference of Major Superiors of Africa and Madagascar. He is the former Principal of Hekima University College in Nairobi. He has written extensively on HIV and is cited several times in this study.

want to briefly consider some ways in which 'HIV in the body of Christ' as a theological claim has been both challenging and enlightening. A critique of three historical events will suffice to make my point at this stage.

The first major Christian conference in this country entitled 'The Catholic Church and AIDS' was held at the Dominican House at Spode in early November 1986, sponsored by the Dominican Order, with the approval of the Catholic Bishops and the collaboration of the Terrence Higgins Trust (THT) (Pendergast, 1990).²⁹ There are three aspects of the Conference that I want to mention. First, the voices of people living with HIV and Aids were heard. The participation of people with Aids 'demythologized' Aids by virtue of the encounters that could only happen because they were given a central role. Amongst others there was Benedict, whose body bore the purple lesions of Kaposi's Sarcoma,³⁰ and "made of his suffering a preaching" (Radcliffe, 1987, p.118).³¹ He told his story and answered questions from the clergy, doctors, social workers, religious sisters, and others who attended. At the close of the day this 'church at Spode' gathered around Benedict, and they prayed with him and for each other as he was anointed with oil. Second, earlier Fr Michael Lopes OP, the co-ordinator of the Aids ministry for the Archdiocese of San Francisco, spoke movingly about accompanying people with Aids. He stressed that they have a ministry to the Church, and recalled how whilst holding the body of a man dying of Aids he knew, in that moment, that he was holding the body of Christ. There should be an icon of Christ covered with Kaposi's Sarcoma he said. Third, the conference issued a statement which included the sentence, 'we ask our bishops to give their active support to this work of Christ; for it is His Body which has AIDS' (Radcliffe, 1986). This is the first time that the Body of

²⁹ A small number of Christians had organised themselves as the 'AIDS Faith Alliance' as an ecumenical group, and included members of the clergy and held a conference earlier, in the summer of 1986 (Pendergast, 1990). I name this as the first Christian Conference because it had formal institutional support at the time. Martin Pendergast was a founder member of CAL and CAPS. He remains one of the most prominent British public figures and activists in church ministry in regard to the LGBT community. He is also a contributor to the CAPS *Positive Faith* project (see bibliography).

³⁰ Kaposi's Sarcoma is a rare type of cancer which usually produces purple lesions on the body. It is Aids defining disease.

³¹ Personal details for Timothy Radcliffe are given in chapter four. He is a Patron of CAPS and has participated in CAPS' *Positive Faith* online video HIV education project. He contributed to the first collection of theological responses to Aids published in Britain (Cosstick and Radcliffe, 1987).

Christ, therefore the Church, was named theologically and publicly as infected with HIV, living and dying with Aids.³²

Three years later, in 1989, the recently formed charity, Catholic AIDS Link (CAL) sent three delegates to the first Vatican conference on Aids. Here, in contrast to Spode, people living with HIV or Aids were conspicuous by their absence. CAL and representatives from Catholic Aids ministries in the United States had written to the Vatican to request that the Conference be addressed by people openly living with an HIV diagnosis, but to no avail. The line-up of speakers included prominent clergymen, academics and scientists, but the timetable allowed no space for the concerns of people living with HIV or Aids to be expressed.³³ This was reflected in the presentations, which included an insistence on the prohibition of condom use in marriage even for sero-discordant³⁴ couples. Monsignor Caffarra³⁵ recommended abstinence in such cases, but accepted that “there may...be situations in which conjugal sexual relationships can be ethically justified” for example, when not to do so would risk one of the partners committing adultery (Caffarra, 1989). His argument would later be paraphrased as ‘chastity or death’.³⁶ Asking ‘Is AIDS a Divine Punishment?’ Prof. Buttiglione³⁷ referred to gay sexuality as ‘invented’ and unnatural. He cites the “risk of contagion...not associated with heterosexual behaviour” as firm evidence that ‘obviously’ contradicts any claim for the ‘normality’ of gay sexuality and argues that Aids is a consequence of the failed sexual revolution of the sixties and seventies (Buttiglione, 1989). Fr. Honings³⁸ confidently stated that “AIDS is nothing else but one of the numerous and disastrous consequences of disordered sexual behaviour” (Honings, 1989). Leaving

³² This sentence was repeated in 1987 by the Catholic Bishop’s Conference of Kenya in their first statement on HIV and Aids (Catholic Bishops of Kenya, 2006, p.47). Since the turn of the century, theological interpretations of the body of Christ with HIV or Aids have become more commonplace (Byamugisha, 2012). In 2003 the Anglican Primates sent a pastoral letter to the entire Anglican Communion in which they stated ‘the Body of Christ has AIDS’ (van Klinken, 2012).

³³ The lack of representation or meaningful involvement of people living with HIV attracted protests on the opening day of the Conference which in turn attracted international publicity (CAL News, no. 4, March 1990).

³⁴ Where one spouse is infected with HIV and the other is not.

³⁵ Caffarra was Professor of Moral Theology and Dean of the John Paul II Institute for Marriage and Family Studies at the Lateran Pontifical University, Rome.

³⁶ CAL News, no. 4, March 1990.

³⁷ Buttiglione was Vice Rector of the International Academy of Philosophy, Liechtenstein.

³⁸ Honings was Professor of Moral Theology at the Lateran Pontifical University, Rome.

aside the papers from the scientists³⁹ and with a few exceptions (Cottier, 1989; Picchi, 1989; Tettamanzi, 1989) these excerpts typify the majority of presentations given by moral theologians, Catholic academics and senior clergy, which were preoccupied with restating the episcopal-magisterial teaching of the Church in regard to human sexuality, the importance of ‘traditional family values’, the irrefutability of *Humanae Vitae*, and so on. People living with HIV are mentioned as objects of charity, a danger to wider society, and often as the culpable victims of their own moral failure (Cotta, 1989; Foley, 1989; O’Connor, 1989; Zoungrana, 1989).⁴⁰

However, CAL delegates Peter Larkin (1954-1990), a founder member of CAL, and Fr. John White (1946-2019) were also present. Peter Larkin walked with a stick, and was partially sighted because of a CMV⁴¹ infection. His skin bore the purple lesions of Kaposi’s Sarcoma. He was visibly sick and weak living through his final months of life. John White had been diagnosed with HIV whilst serving as a missionary in Africa. During a reception for delegates Peter Larkin spoke with Archbishop Fiorenzo Angelini.⁴² Larkin identified himself as a person with Aids and challenged Angelini over the lack of opportunity for the voices of people living openly with HIV and Aids to be heard. The Archbishop was defensive and dismissive. ‘How do we know you have Aids?’ he asked, questioning Larkin’s character and credibility. Angered, Peter Larkin shook his walking stick at Angelini, saying, "You're a disgrace to the cloth!"⁴³ At the conference, John White became increasingly frustrated by what he was hearing and the lack of discussion or possibility of alternative views being expressed. During a break between speakers, on the first day, he stood near the podium and raised a banner which read ‘The Church has AIDS’. He had not intended to speak, but at the last minute, in a

³⁹ Prominent speakers included Profs. Robert Gallo and Luc Montagniere, both credited with discovering HIV, and Prof. Jonathan Mann, Director of the World Health Organisation Global Programme on AIDS. The presentations based upon scientific research made by them were factual and not controversial.

⁴⁰ Variations of these arguments continue to be made. Former director of the Harvard AIDS Prevention Project Edward Green’s research (2003; 2006; 2011) is often cited in defence of moral arguments and statements, especially those of Pope John Paul II and Pope Benedict XVI that argue for behaviour change, and prioritise fidelity and abstinence, in opposition to condom use as most effective for HIV prevention. See also Hanley, 2005; Fisher, 2009; Hanley & Irala, 2010; and for a review of the evidence see Charania et al., 2011; von Sadovszky et al., 2014; Marcel et al., 2016.

⁴¹ The Cytomegalovirus, is an Aids defining infection that leads to blindness.

⁴² Angelini was President of the Pontifical Council for Pastoral Assistance to Health Care Workers who organised the conference.

⁴³ Additional detail confirmed by email from Martin Pendergast on May 21st 2019. See also ‘Pope Asks Global AIDS Effort’ *The New York Times*, Thursday Nov 16th, 1989.

loud voice he announced: “I am living with AIDS, and people with AIDS have no voice at this conference.” Quickly the Vatican security men bundled him out and he was detained by the Vatican police. ‘The Church has AIDS’ was the headline relaying the story in the next day’s press, adding to the already controversial worldwide coverage of this conference (Parmelee, 1989; Garfield, 1995, pp.169-171).⁴⁴

Archbishop Desmond Tutu invited the artist Maxwell Lawton (1956-2006), who was living with HIV, to set up his easel in the Cathedral in Cape Town, and commissioned him to paint a picture of Christ with Aids, following Lawton’s previous painting of Christ marked with the lesions of Kaposi’s Sarcoma on His body: ‘*Man of Sorrows: Christ with AIDS*’ (1993).⁴⁵ Some people who visited while Lawton painted were intrigued. Others spat at him in disgust at his presence. When an image of his new work, an icon of the same title, was published on the front page of the *Cape Times* in December 1994 it caused worldwide controversy. Lawton was given police protection after someone came looking for him to “rid the [Cathedral] of the heretic artist.” Bishop Tutu responded by defending both Maxwell Lawton and the painting as theologically correct. Maxwell Lawton died from an Aids related illness in 2006 (Kurian, 2016, pp.29-30).

These three stories each speak in diverse ways about embodied encounters with HIV. The bodies of people living with HIV and the body of Christ are the central figures. It is how the relationship between the two is perceived and enacted within the church gathered in each

⁴⁴ Simon Garfield is a British journalist who wrote one of the first historical accounts of HIV and Aids in Britain in 1994, including an interview with Fr. John White. Berridge (1996) and Garfield (1995) are primary historical sources for the following chapter. Additional detail from Fr. John White in conversation with me during a visit during his last months of life in 2018 at Nazareth House Care Home, Hammersmith, London, and from CAL News, no. 4, March 1990 and email and conversation with Pendergast above. John White was not released by the Vatican Police until Krystyna Fuchs, the third CAL delegate, and the Kiltegan Fathers confirmed that he was a real priest. Partly in response to the treatment of Peter Larkin and John White, and certainly in response to the theological tone set at the Vatican conference, which received a great deal of negative press coverage world-wide highlighting judgmental and moralising statements, CAL produced badges and T-shirts for sale which said ‘Those who think AIDS is a Plague Sent by God Have Never Met My God’ & ‘The Body of Christ has AIDS’ (CAL News, no. 8, 1991). This is the first time that the exact theological phrase ‘The Body of Christ has AIDS’ was made in any public way. Given the impact and potentially disturbing nature of the use of this exact phrase, as discussed in this chapter, I think it noteworthy that this theological truth was first articulated so directly and ‘unapologetically’ by HIV activists via an item of popular culture before it was presented as academic theology or used by a member of the Hierarchy. See also ‘Vatican AIDS Meeting Hears O’Connor Assail Condom Use’ *The New York Times*, Nov. 14, 1989.

⁴⁵ Available at <http://www.maxwelllawton.com/Flash/gallery.html> & for the St. George’s Cathedral icon <http://www.maxwelllawton.com/Flash/gallery.html> [Accessed Nov. 2018].

location at a particular time that is revealing. For example, Benedict's body is a site of pain and healing. The dying man embodied Christ for Lopez. Peter Larkin asked to be understood and the body of John White demanded to be seen.

Through these three stories of HIV encountered within the body of Christ various responses are identifiable. As Benedict was physically placed at the centre of the church gathered in prayer at Spode, the body of Christ living with HIV was touched and embraced through him. Peter Larkin's visibility at the Vatican conference provoked a response to deny him and silence him. John White's protest at the centre of the Institutional Church was threatening and disruptive and the power of the Church was exercised to control the scandal he embodied. By inviting Maxwell Lawton to St. George's Cathedral Archbishop Tutu symbolically invited HIV into the whole Church, asking his brother in Christ to 'preach' through his embodied presence and bringing to effect the wish of Michael Lopez that that the Aids marked body of Christ be raised up and revealed as a focus for contemplation and devotion.

As I will describe in greater detail in chapter two the reality of HIV in the body of Christ has been disturbing, disruptive, and challenging within the Church. What is indisputable is that whether acknowledged and welcomed or denied and rejected, the embodied presence of a sister or brother living with HIV has the potential to evoke a powerful response – sometimes hostile and fearful, sometimes as a type of conversion experience or graced encounter with Christ. That this is so will be evident in my interviews in chapters four and five.

I am not proposing that this thesis enables embodied encounter in the way that I have just described. Truly embodied encounter occurs when persons meet in the flesh. However, I am presenting this study as a type of encounter, or a series of encounters, with arguments supported by evidence, which may deepen understanding and contribute to public knowledge. Again, the transformational power of such encounters will be repeated throughout this study. I am arguing that without any encounter, the theological learning or divine revelation that might be mediated through the experiences of our sisters and brothers living with HIV cannot happen.

Tracking HIV as a phenomenon in the Church historically in chapter two and developing the argument in chapter six, I will make the case that the real presence of HIV in the body of Christ in this country is not acknowledged, and therefore not considered theologically, even

as an intellectual exercise, and that the embodied encounter with HIV in the Church is a rare event. I will make the case in chapter two that HIV is more usually considered as something that happens elsewhere, or as an event from the past, something distant, creating the opposite conditions required for encounter, namely proximity, thus allowing for a denial of HIV and those affected as a concrete reality in our midst. Three further examples will suffice to make this important point at this stage.

At the 2009 conference '*AIDS: A Sign of the Times?*'⁴⁶ theologians from around the world gave excellent presentations in response to this question. I attended along with a small number of members from the Positive Catholics community, including Tiago, who I will introduce more fully in chapter five. Afterwards he commented that he had felt like taking his shirt off to show those present what Kaposi's Sarcoma looked like in the flesh, particularly during a presentation from a religious missionary sister that included a slide show depicting the bodies of African women and men suffering with this rare cancer. As we were told about the experiences and hardships faced by African women in Uganda, an African woman living with HIV sat in the same room and did not feel acknowledged. Their feelings were in response to the fact that whilst the Conference heard about the situation in Africa, the Ukraine, and other 'developing nations', no speaker addressed the question with any reference to HIV and Aids within our own city or country. It was as though HIV in our midst had not been considered theologically relevant.⁴⁷

That *The Tablet* published a special edition on international aid to mark the fiftieth anniversary of Cafod, ironically on World Aids Day, December 1st 2012, without a single mention of HIV or Aids, illustrates that even in the context of international development, this important aspect of life may be overlooked.⁴⁸ Similarly, that theology concerned with

⁴⁶ Heythrop College, London, Saturday 14th November 2009. Kevin Kelly who is interviewed later in this study attended. The main conference organiser was Gillian Paterson whose doctoral dissertation explored HIV and Aids Stigma. She has worked closely with the World Council of Churches and her work is cited in this study. Ann Smith, the lead officer for Cafod on HIV from 1993 to retirement circa 2010, whose work is referenced also attended. Julie Clague, interviewed later gave a presentation as did Agbonkhianmeghe Orobator, SJ whose work is cited in this study.

⁴⁷ During the conference lunch break, I made an impromptu and unplanned announcement. I invited anyone who wished to, to join me for an informal discussion about the ministry of Positive Catholics in England. After the conference, sensing the need for a 'de-brief' I invited our small group to a local café where we had tea together, and these feelings were expressed.

⁴⁸ I wrote to the editor of *The Tablet* at the time to highlight this omission although my letter was not published. I was relieved to read a letter from Kevin Kelly, which made the same point published later (Kelly,

the lives of gay people can be published without reference to HIV (Hinze and Hornbeck, 2014; Martin, 2017)⁴⁹ indicates a lack of historical awareness and an ignore-ance of how gay men remain especially affected by HIV today. These brief examples evidence a type of denial enabled by distance and time, the reduction of HIV to a medical problem and the rarity of embodied encounter.

Bodily theology

In her study *Enfleshing Freedom* (2010) M. Shawn Copeland has privileged black female bodies as a locus for theological reflection. She states that: “the body shapes human existence as relational and social...the creativity of the Triune God is manifested in differences of gender, race, and sexuality...solidarity is a set of body practices; and...the Eucharist orders and transforms our bodies as the body of Christ.” Following Copeland, in this thesis I approach the bodies of men and women living with HIV as a site and mediation of divine revelation (Copeland, 2010, p.2; Barnsley, 2016). Meeting the main subjects of this study, reading their words and listening to their voices provides an encounter with HIV through their embodied experience, within which a divine Word may be revealed.

I will argue in chapters seven and eight that the experience of an HIV diagnosis may be understood theologically as sharing in the Passion of Christ. In chapter seven, the words of my interviewees will describe how they have come to embody the scandal of the cross of HIV. I have already referred to the painful marks on the bodies of Benedict and Tiago, and in

K.T., 2012a). In 2012 there were an estimated 34 million people living with HIV and Aids globally. Today an estimated 37 million people are infected. The vast majority of people living with HIV are located in low- and middle- income countries, with an estimated 66% living in sub-Saharan Africa. See AVERT at <https://www.avert.org/global-hiv-and-aids-statistics> [Accessed January 2019].

⁴⁹ In Hinze and Hornbeck, 2014, a collection of seventeen essays, I could find just one reference to HIV and Aids as a passing detail of previous experience (Falcone, 2014). The 2017 publication of *Building A Bridge: how the Catholic Church and the LGBT Community can enter into a relationship of respect, compassion, and sensitivity*, by James Martin, SJ, which I consider to be thoroughly uncontroversial theologically, argued as the title indicates, for the need for mutual respectful encounter and listening, between gay Christians and others in the Church, particularly members of the hierarchy, in order to enhance understanding and move towards reconciliation between Christians with opposing views. The publication of the book generated controversy, and is a typical manifestation of the so called continuing ‘culture wars’ and evidences the polarised theological, ecclesiological and political stances of groups within society and the Church – not only but especially within the USA (Green et al., 2006; Gonzalez, 2017; MacDonald, 2018). Along with Timothy Radcliffe and many others including cardinals, bishops and theologians, Martin is cited in an open letter accusing Pope Francis of committing heresy. The letter uses Martin and Radcliffe, as examples of Pope Francis “protecting, promoting and helping heretics... [and] publicly praising individuals who have dedicated their careers to opposing the teaching of the Church and the Catholic faith...[which] communicates the message that the beliefs and actions of these individuals are legitimate and praiseworthy” (Buscemi, et al. 2019).

these chapters particularly I will make visible HIV positive bodies in pain. I am conscious of wanting to avoid a kind of indulgence of pain and suffering that voyeuristically confines people living with HIV to the role of victim and the object of pity. However, I agree with Copeland who has argued that to “pass over...sorrows imperils humanity as well as theology” (Copeland, 2010, p.3). Also, in keeping with Copeland, to re-member the suffering undergone by others fulfils an obligation to the memory of those HIV positive sisters and brothers who have gone before us, marked with the signs of faith, not only but in a particular way, those interviewed for this study who have since died. Through the bodies of black women Copeland reveals the bearing of, resistance to, and freedom from the injustices of racism. Considering the place and actions of black women during the time of slavery she fulfils her responsibility to these dead by challenging her readers to “respect the dignity of suffering that has accumulated in history and to translate that respect into compassionate practices of solidarity...that address the crusted residue of slavery in contemporary and global re-enactments of violence against black bodies” (Copeland, 2010, p.4).⁵⁰ In this study, similarly, I reveal the suffering bodies of women and men who have been diagnosed with HIV with a similar challenge in mind for the reader of this thesis. Through their experience the contemporary ‘crusted residual’ effect of HIV stigma will be revealed, and the deep roots it has in sexism and homophobia will be apparent. I will return to some of these questions in my concluding chapter.

Lastly, when Thomas encountered the risen Christ in the upper room, he touched the wounds in the body of his Lord and Saviour.⁵¹ When Jesus appeared amongst the disciples He did not return to them unblemished, whole and new, but scarred. His still wounded body testified to His experience of Passion and death on the cross, and His overcoming of that in Resurrection. In Part II of this study I will reveal through the bodies of women and men who are living and have died with HIV and Aids, the wounds that testify to their passion experience in union with the Christ who bared his side for Thomas to touch. I will describe some of the ways and practices by which these Christians, in communion with each other become the same body with wounds still visible, that Christ offered to Thomas. I will argue

⁵⁰ Copeland was associate Professor of Theology at Boston College and a former President of the Catholic Theological Society of America.

⁵¹ John 20:24-29.

that within Christian community when wounds are offered for each other, through a shared vulnerability, healing and new life is encountered.

In these ways, via these encounters, keeping alive the memory of the passion undergone by our sisters and brothers living with HIV is also to keep alive the memory of the Passion of Christ, who embodies God's constant saving love for all of humanity.

Summary and conclusion

This thesis then, argues that the situation of people living with HIV can be understood as a type of passion experience. My argument proceeds by way of a series of encounters that I offer in this study. In this chapter, I trust that the reader will feel that they have encountered me. I have described my motives for undertaking this research and explained how I understand this work to sit within the category of practical theology. In the following two chapters the historical and present context of HIV in this country will be encountered, and in chapter three the epistemological framework and theological approach with which I proceeded with this research methodologically will be described in some detail. In chapters four and five I will introduce first the theologian-practitioners and then our principal subjects, Christians living with HIV, whom I have interviewed for this study. In both chapters I have chosen to present the material minimally mediated by me, not to overburden the reader, but because I want to allow for the possibility of encountering each of these people in their own words. Given that the voices of people living with HIV are more generally silenced, and as this is the first study to seek to uncover the theological sense that these Christians have made of their experience, I wish to present as fully as possible, their own reflections and theological interpretations.

I have explained that together chapters one to five contextualise this study as a process of inquiry and offer the historical background of the phenomenon which is important both in terms of remembering the past and also to understand the present situation and experience. The complex theological landscape of HIV, the challenges and issues that have been actualised within the Church, remain relevant and contextualise the argument I make in Part II.

In chapter six I will describe how myths and misunderstanding can serve as obstacles to any encounter with both the existential phenomenon of HIV, and more importantly with any

person living with HIV, before proceeding to the encounters of my subject-participants with HIV through their own experiences of passion, cross and resurrection in chapters seven, eight and nine.

In this chapter I have argued that the historically, sociologically and theologically rich descriptive encounters with lived experience that I will present in this study are required. I have begun to describe some responses of the Church historically above, and I will continue in chapters one and two to tell the story of the impact of HIV and Aids and the church's responses for the first time in a single study. I have introduced the argument that a type of forgetting reinforced by a lack of engagement in regard to HIV in the Church, justifies this study. Because HIV is not routinely encountered in this country by most people there is a need to remember what has been forgotten. I will provide evidence of how communities of people living with HIV and Aids in the past, have occupied a site of graced encounter, embodying fellowship and solidarity, serving as an example for the Church, and a locus of conversion and spiritual encounter for individuals. As I will argue, many of the issues and challenges of HIV as a reality within the body of Christ that were first brought into view in the nineteen eighties are still evident in today's church.

PART I

HIV in Context

“Everything was uncharted territory for all of us.

Events were happening too quickly to bear” (Kramer, 1995, p. xxxiii)

Chapter 1. Historical context: Considering HIV in society then and now

1.1 Introduction

In this chapter I have drawn from the historical and social science literature to provide an overview of how the UK government and wider society responded to the emergence of HIV and Aids.⁵² To understand the phenomenon of HIV in church and society today it is necessary to be reminded of the past. As I will argue in chapter six, our memory of the history of HIV and Aids effects how we understand the present situation. Following this historical account I will provide a summary of the present medical and societal context and describe the ways in which the situation today differs from that of previous decades. This chapter provides the contemporary social, epidemiological and medical context in historical perspective, and is important for an appreciation of the Church responses that I will describe in the next chapter, and necessary in order to understand the experience of my main interviewees in chapter five, and the theological interpretation of that experience throughout Part II. As I will show in later chapters, the meaning(s) attached to HIV and Aids in the past, are re-membered in the bodies of people diagnosed with HIV today.

1.2 Societal responses 1982 – mid 1990s: Gay men act for themselves and others.

If my own relationship with the emerging reality of HIV and Aids was one of reluctant engagement in the eighties, others were quicker to act and respond. As I have indicated above, UK government and societal responses within the first decade were inter-related with the emergence of HIV within the USA. The communities most directly affected were the locus of first reaction. Gay men in both the United States and the UK gathered together in order to formulate their own responses in 1982.⁵³ Established that year the Terrence Higgins Trust (THT) has grown to become the largest provider of voluntary sector HIV services in the UK. At a time of great confusion and anxiety the Lesbian and Gay Switchboard organised the first public conference in the UK on Aids in 1983 and opened a

⁵² Important historical sources are Berridge (1996); Garfield (1994) and the Social Aspects of AIDS series edited by social scientist and educationalist Peter Aggleton published between 1988 and 1995 in bibliography.

⁵³ They included the San Francisco AIDS Foundation (SFAF), AIDS Project Los Angeles (APLA), and Gay Men's Health Crisis (GMHC) in New York. In November 1982 the first UK Aids organisation, the Terry Higgins Trust (later renamed the Terrence Higgins Trust, THT), was formally established. Each of these organisations continues in some form today. Historical timelines of HIV and Aids globally and regionally are accessible online via AVERT and other websites listed at the end of bibliography under websites.

dedicated helpline to take calls and offer information (Garfield, 1995, pp. 36-37).⁵⁴ The institutional appearance and status of these organisations today might lead us to forget how they began. Invariably, they started as small groups of frightened friends, huddled together in someone's home.⁵⁵ THT was set up by a few friends of Terry Higgins, one of the first people to die of Aids in the UK, and Terry's partner, Rupert Whitaker, in a central London flat. The peer support movement Body Positive (BP) began in London in 1985 and soon had groups operating throughout the country.⁵⁶ Gay organisations in the UK were at the forefront of pressing for adequate policy responses from the government. The London Lighthouse in Ladbroke Grove and The Landmark in Lambeth were two examples of the kinds of support centres that soon replicated around the country (Berridge, 1996, pp. 169-171).⁵⁷ Offering peer support groups, counselling services, palliative care and alternative therapies, Aids gave rise to new models of support for those living with and dying from a terminal disease. The instigators, volunteers and paid staff in these new centres were in the

⁵⁴ Many gay men in the UK were influenced and aware of developments in the USA, partly because many had visited NY and San Francisco for example, and had established contacts and links with communities in the USA. See for example Watney, 1994, preface. The Switchboard helpline was launched following a broadcast by the BBC Horizon program entitled "Killer in the Village" which focussed on the Greenwich Village district of New York - the so called 'Gay Village'.

⁵⁵ For example, the co-founder of gay Men's Health crisis (GMHC), the writer Larry Kramer, hosted their inaugural meeting in his flat in New York, where they elected Paul Popham as their President. At the time, Popham did not want his role in the new organisation to become public knowledge, for fear that his colleagues at work would discover that he was a gay man (Shilts, 1988, p. 120). By 1987 Kramer was involved in setting up the group AIDS Coalition to Unleash Power (ACT UP). This direct action group is associated with highly public campaigns to gain equal rights for people living with HIV and Aids, and the allocation of greater resources to combat the pandemic (Cohen, 1998; Gould, 2009). Their legitimate fear that Aids was not being addressed adequately in the USA gave rise to anger, civil disobedience and street protest (Kramer, 1995, pp.127-139; Cohen, 1998, pp.15-68; Engel, 2006, pp.109-112; 131-145; Gould, 2009, pp.49-50). See also documentary films: France, dir. 2012 'How to Survive a Plague' & Hubbard, dir. 2014 'United in Anger: A History of ACT UP'. Public protest and activism was intense in the USA not only to raise awareness but also to put pressure on the federal government to increase funding for research and increase access to health care for people living with HIV or Aids. In part because the National Health Service (NHS) provided available treatment free at the point of need within the UK activism was expressed differently. Although the Switchboard and THT were at the heart of discussions, and fierce debate, with government ministers and health professionals in formulating responses, the more combative approach of ACT UP in the USA was not adopted in the UK. Speaking at the International Conference on AIDS in 1988, Tony Whitehead the first Chairperson of THT said that Aids activism in the UK had not included "any kind of direct challenge to the inadequacies of AIDS funding and government policies....Our immediate response to the tragedy of AIDS has been to rush off to hold people's hands at bedsides. We have not taken our fight out onto the streets as has happened in the United States" (Berridge, 1995, p.165).

⁵⁶ Initiated by two gay men, Jonathan Grimshaw and Peter Randall, they also met initially in Grimshaw's flat, before locating to premises in Earl's Court (Berridge, 1995, pp.154-155).

⁵⁷ Virginia Berridge is an academic historian and public health expert and a leading authority on the history of HIV and Aids in this country.

majority, gay men.⁵⁸ Most often, it was the people infected and directly affected that led the way in creating innovative programs of care and support, prevention and education (Warwick, 1993). Gay men, intimately confronted, were the first to act (Berridge, 1996, pp. 14-23; Hallsor, 2017, pp. 57-58).

1.3 HIV veiled in secrecy in public view

Through the eighties the numbers of people diagnosed with HIV or admitted to hospital with one of the opportunistic infections characteristic of Aids, grew steadily. Deaths from Aids rose. Each person was someone's daughter or son. Each of these people had friends, family, colleagues. Increasingly therefore, family members, individual parishioners and clergy, were unavoidably confronted. I know of many stories. I remember the parish priest called to baptise and later bury, the baby born infected. This same priest later buried the child's mother, and comforted her parents and the surviving children as they tried to cope. In a large country house there was a sister who waited at the bedside of her brother who had returned to the family home to die. Although they lived in a grand estate with servants, caring for a brother with Aids was a family matter. The servants need only know that he was unwell. In a Catholic primary school, the parish priest and the headmaster advised a mother that perhaps it would be better for her child if he did not return to school next term.

The stigma that surrounded HIV meant that interpersonal disclosures of HIV diagnosis were mostly very private and boundaried by a strict confidentiality. Confidentiality however, is an inadequate term for the kind of secretive encounters that I am describing. The components of stigma - fear, shame, prejudice and ignorance - meant that the knowledge that a family member, friend or parishioner had Aids was usually confined to small numbers of people. These early encounters were mostly hidden from wider public view, veiled by a fearful secrecy. When HIV impacted on personal relationships, it is as though the accompanying drama was played out behind the scenes.

⁵⁸ The Lighthouse in London opened in 1988 and made a special contribution to the Hospice Movement providing specialist in patient care for people with Aids, at a time when there was some resistance to accepting PLWHA within the mainstream Hospice movement (Berridge, 1995, p.157). The Landmark, also in London, like the majority of regional support centres did not have in-patient facilities. Other voluntary sector support organisations were established from the mid-80s onwards in Cardiff, Bristol, Cambridge, Brighton, Exeter, and elsewhere, most often developing from existing gay organisations (Berridge, 1995, p.155). For a volunteer's account of life at The Lighthouse see Cantacuzino, 1993; for the founders account see Spence, 1996.

By the close of 1985 of the 275 cases of Aids reported within the NHS, 144 had died. Epidemiological projections were sufficiently concerning to compel the UK government to launch a nationwide health promotion campaign in 1986. Leaflets warning ‘Don’t Die of Ignorance’⁵⁹ were delivered to every household in January 1987 (Fowler, 2014, pp. 1-37).⁶⁰ At the same time a media campaign brought HIV and Aids to wider public attention. As the number of people diagnosed with Aids in the UK exceeded 1000 in 1987, Princess Diana led the news bulletins when, challenging contagion myths, she appeared holding the hand of an Aids patient. Princess Margaret opened the London Lighthouse in 1988, and Aids entered the nation’s living rooms in the early nineties when the character Mark Fowler received his HIV diagnosis in the popular TV soap ‘Eastenders’.

At first HIV and Aids was characterised as ‘the gay plague’, and many imagined it only affected ‘promiscuous’ gay men in the USA. A decade after Terry Higgins died in St. Thomas’ hospital in 1982, HIV and Aids was centre stage in the public imagination. It was understood that HIV and Aids was affecting UK society and was here to stay. HIV demanded a response.

1.4 Governmental responses

Official public responses took some time to formulate. Authorities only gradually came to appreciate that Aids was a national and trans-national public health issue. A detailed presentation or analysis of the social and political history of Aids is beyond the scope of this thesis, but it is important to be reminded of how different public policy and social attitudes

⁵⁹ The original leaflet is reproduced in Fowler, 2014, pp.277-282. Norman Fowler was Secretary of State for Health in Margaret Thatcher’s government 1981-1987 and was a main actor in the national campaign. He remains a member of the All Party Parliamentary Group on HIV and Aids.

⁶⁰ In 1986 the government ran the first national public health campaign with full page newspaper adverts that had the title ‘Don’t aid AIDS’. Every household in the country received leaflets with the slogan ‘Don’t die of Ignorance’ in 1987, which was part of a wider media campaign which also included the screening of the (in)famously alarming television adverts. The dramatic nature of these campaigns reflects the sense of urgency and panic that existed at the time. Virginia Berridge (1996) identifies this period as one of ‘Wartime Response’. However, the television ads were controversial because of the deliberately terrifying cinematic style they employed. Although the sense of urgency made a strong tone of warning designed to shock understandable, health education specialists assert that fear-based campaigns are less effective as a means of encouraging behaviour change than campaigns which are less alarmist and more concerned to convey accurate factual information. Emotive warnings may actually serve to obscure relevant information. They also have the unintended effect of increasing the stigma associated with HIV which further marginalises infected and affected people and hinders broader prevention and education efforts. These ‘Iceberg’ and ‘Tombstone’ ads can be viewed on the web and are listed at the end of my bibliography (Films and videos). See also Berridge, 1996, pp.112-113; Washer, 2010, p. 54; Griffin, 2000, pp.56-77, which discusses this campaign within the broader health promotion context.

were in the first decade of Aids. It is easy for society to forget that Aids and the implications of the pandemic once seemed as threatening as nuclear war did in the 1960s and 70s (Berridge, 1996, p.107). By the early nineties no adult in the UK, other than the most ignorant, could be left in any doubt that HIV and Aids was a massive and potentially deadly threat, with ruinous consequences for whole societies.⁶¹

As already stated Aids was first defined and understood in the UK via the experiences of gay men here and in the USA. The medical, governmental, media and religious responses in the USA also influenced responses in this country. So, to further appreciate the wider context I will describe public reactions in the UK with reference to some wider characteristic features, principally from the North American context.

Within the medical-scientific communities, the first use of the term 'AIDS' was in 1982. HIV was identified and a diagnostic test developed by 1985. The fact of Aids, the identification of the virus, and the routes of transmission were known. But it was not until 1986/7 that Aids was officially understood as a crisis and came out of the wings and onto the stage of public concern in the UK (Ferlie, 1993, p.206; Street, 1993, p.224). Virginia Berridge describes the years 1981-86 as characterised by "surprise and shock, with relatively little official action, succeeded in 1986-87 by a brief period of 'war time emergency' when politicians publicly intervened and AIDS was established as a high level national emergency" (Berridge, 1996, p.78; Berridge and Strong, 2002, p.3; Harden, 2012, p.107).⁶² This sense of emergency was reflected in the establishment of a special Cabinet Committee for Aids, and in the allocation of UK government funding for care, education and research which was increased by tens of millions of pounds (Street, 2002, p.226).⁶³

⁶¹ For a list of mass media campaigns carried out by the UK government in the years 1986 – 1993 targeting the general population; young people; gay men and black and minority ethnic groups see Berridge, 1996, p.196.

⁶² Victoria A. Harden is an American historian who has been involved in documenting the history of HIV and Aids since the late eighties.

⁶³ John Street notes that the public education campaign of 1987 gained by £20 million. However, this fiscal response to the crisis is qualified by the criticism of the government's policy formulation and implementation, contained in the House of Commons Select Committee on the Social Services 1987 Report (Street, 2002, pp.226-227). It is interesting to note the contrast between the financial commitment to HIV prevention set against resources for patient care and research. Member of Parliament David Alton writing in 1987 states that up to the end of 1985 only £2 million had been allocated for patient care and research combined. He notes the increases planned for 1987-88 and calls them significant but still inadequate given predictions that Aids care would cost between £20 and £30 million in 1988. As a concrete example he cites the case of one Regional Health Authority, South East Thames which had requested £4 million from government funds for 1987. He

One reason for these delayed reactions is simply that Aids came as a surprise to the medical and scientific communities. A transmissible agent that killed people by attacking the immune system had not been known before HIV, and scientific research to understand such an agent had not been conducted before (Harden and Rodrigues, 2002, p.189; Mort, 2000, p.168).⁶⁴ Barnett and Whiteside point out that the last global epidemic prior to HIV and Aids was the influenza epidemic of 1918 -1919. There was little institutional memory of “killer epidemics” (Barnett and Whiteside, 2006, p.29).⁶⁵ Add to this the fact that the numbers of people being diagnosed increased at an alarming rate, and it is understandable that those on the front-line of the medical response felt overwhelmed by this new disease.⁶⁶ Aids caught us unaware and aroused intense fears partly because it exposed the impotence of modern medicine, just when we had begun to believe that science had rid the Western world of infectious diseases for good (Grmek, 1990, p.41; Allen, 2002, p.119).⁶⁷

There is a second less forgiving interpretation. Decisions in terms of research, prevention, and care and support, were circumscribed by the political and moral landscape of the eighties. Politically, very recently elected conservative governments held power in the USA and the UK. Under President Ronald Reagan and Prime Minister Margaret Thatcher the

states that they received just £700,000 and points out that £850,000 would be needed to pay for heat-treated factor VIII for haemophiliacs alone (Alton, 1987, pp.176-177).

⁶⁴ Frank Mort is a British cultural historian.

⁶⁵ Tony Barnett is a British academic specialising in the social sciences of Infectious diseases. Alan Whiteside is a South African academic specialising in the social impact of HIV and Aids.

⁶⁶ Epidemiological data was showing rapid increases in new cases of Aids globally. In the USA where clinical data was first collected there had been 270 recorded cases of whom 121 had died in 1981. By close of 1983 cases in the USA had risen to 3,064 of whom 1,292 had died. In the UK by the end of 1983 there were 29 recorded cases rising to just over 2000 cases in total by April 1989 with over 1000 deaths. By the end of 1993, there were an estimated 2.5 million AIDS cases globally (Berridge, 1996, p.1; AVERT under websites in bibliography). Since the start of the epidemic, an estimated 77.3 million people have become infected with HIV and 35.4 million people have died of AIDS-related illnesses globally. In 2017, 940,000 people died of AIDS-related illnesses. This number has reduced by more than 51% (1.9 million) since the peak in 2004 and 1.4 million in 2010. Globally there are an estimated 36.9 million people living with HIV in 2017 (including 1.8 million children). Around 25% of these people are unaware of their status (UNAIDS, 2018). In the UK today there are an estimated 102, 000 people living with HIV (AVERT).

⁶⁷ Peter Lewis Allen is an American Jewish writer who I cite frequently in this study. Reading his ‘The Wages of Sin’ (2002) represents an important stage in my research and influenced my interviews with theologians in chapter four. Allen’s own encounter with Aids, and the deaths of so many of his friends; not least that of his former partner, a Scottish Presbyterian man, caused Allen to ask why the association between Aids and sin was so powerfully and often expressed. His account of the ways in which sex, disease and sin have been historically linked is the result. He writes that he hopes his book will help readers “become aware of the huge cost of seeing disease as a punishment for sin” (2002, pp.xiii-xxiii). I consider this book an important source for this study.

institutional responses are criticised for often being inadequate, and for failing to respond as soon as they might have (Mort, 2000, p.169; Lune, 2007, pp.21-28; Gould, 2009, pp.11, 137-138). Why? There was and is a view, that the State has no business interfering with the private sexual lives of citizens. This impacted upon the content and timing of the public health promotion initiatives throughout the eighties and beyond. In the earliest years, there was a reluctance to address the issues. Sex and sexually transmitted infections were a private matter for the individual citizen. No response was the response. During a period when both Thatcher and Reagan espoused 'smaller government' and imposed cuts in government spending generally, there was a significant delay in implementing health promotion campaigns for ideological and budgetary reasons (Harden, 2012, p.35). When health education campaigns did come in 1986-87, they resisted explicit mention of the actual sexual behaviours that transmitted HIV. Sex was not something that we were accustomed to speak about in the public domain.

This reluctance to speak openly about sex and sexuality and therefore Aids, was reinforced by an influential conservative 'moral right', also identified in the USA with the 'moral majority' movement (Allen, 2002, pp. 121-124). Mrs. Thatcher's potent espousal of a return to 'Victorian values' and 'family values' summed up a vociferous opposition to the 'sexual revolution' of the 1960s and seventies. The introduction of what became known as 'Section 28' of the Local Government Act 1988 which banned 'the promotion of homosexuality' by Local Authorities in the UK confused issues further. By this time health promotion agencies understood the need to issue advice and guidance that targeted specific populations such as gay men and drug users with often explicit language and imagery. What the professionals considered effective health education might also have been interpreted as 'promotion' of homosexuality. Teachers, Social Workers and Foster Carers also experienced confusion in regard to the sex education that young people could receive. Were they prohibited from talking about gay sexuality, or HIV and Aids? Section 28 rested on vehement opposition to any claim for equal legitimacy for gay relationships – which were termed 'pretended family relationships'. This clearly identified gay people as being a threat to the family. For many people this legislation was particularly offensive at a time when Aids was killing more and

more gay men (Weeks, 1993, pp. 21-23, 29-31).⁶⁸ In the view of conservative moralists Aids was less a public health crisis and more a moral crisis. Aids was evidence of the links between health, disease, and moral and immoral notions of sex, and manifested a conflict of values in regard to human sexuality (Harden, 2012, p.98; Mort, 2000, p. xiii). The consequences of 'loose living', indiscipline, and the deviant sexual practices of minorities did not deserve much action or sympathy. Explicit mention of sex in public information campaigns was viewed as a threat to conservative family values. The activists and campaigners who protested in the face of public apathy were dismissed by some as opportunists pursuing a militant agenda that sought to promote gay sexuality (Berridge, 1996, pp. 75-77; Harden, 2012, p.108).

1.5 Popular media responses

There is a further component that reveals something about reactions, and that is how Aids was portrayed in the media. On the one hand because Aids affected mostly gay men, in the USA, it merited little attention (Harden, 2012, pp. 164-168). The government's inaction was not subjected to the kind of investigative journalism that might have appeared if Aids was perceived to be a threat to heterosexuals. Larry Kramer's scathing attack of the *The New York Times* details the inadequate coverage that Aids received, as he accuses them of complicity in the deaths of gay men from Aids (Kramer, 1995, pp. 416-429).

Coverage in the popular press in the UK was often alarmist and sensationalist. Much of the language used focused on the threat posed to the general population by people from marginalised groups. Infected individuals were described in terms of their difference from the general population, an impression further reinforced with the identification of 'at risk groups' in the medical, scientific and political establishments. This perception, that Aids afflicted undesirable 'others' – prostitutes, drug users, black immigrants and gay men –

⁶⁸ Jeffrey Weeks is a British historian and sociologist specialising in work on sexuality. He was kind enough to meet with me to discuss this study at an early stage of research. Although there was never any prosecution under the terms of Section 28, it did have an actual inhibiting effect. During the 1980s and until the repeal of Section 28 in The Local Government Act 2003 teachers and others working with young people did 'self-censor' for fear that a breach of the law could lead to prosecution. As a sexual health worker employed by the local Health Authority, specialising in matters relating to looked after children and vulnerable young adults from 1994 – 1999, I have experience of how Section 28 prevented professionals from discussing topics such as 'safer sex' or same sex relationships, with young people. In training courses that I conducted at the time, for social workers and foster carers on the subject of sex and relationships education for young people, the subject of what was and was not permitted always arose and was always a source of anxiety and confusion.

contributed to the delays in action.⁶⁹ It certainly contributed to complacency in terms of behaviour change at the interpersonal sexual level. Such attitudes work against HIV prevention messages. If a straight middle class young white man from a 'good family' thinks of HIV as only occurring amongst others who are not at all like him, and not at all like his nice girlfriend, then he is less likely to consider himself at risk of infection, and therefore less likely to consider any need to alter his own behaviour. If his girlfriend has the impression that a person with Aids can be identified by the colour of their skin, or that someone is not HIV positive because they are 'clean living', respectable and straight, then she is less likely to insist that her boyfriend uses a condom. When assumptions such as these are made the need to mention HIV or discuss safer sex can be dismissed; a particularly tempting option if one lacks the language, skills, or confidence to talk about sex before engaging in sex.

In contrast to much of the popular press coverage, British broadcasting companies contributed to the public health education campaign with a coordinated 'National Aids Week' across both ITV and BBC television and radio channels in February 1987. Such a coordinated response to what had come to be understood in government as a national emergency was unprecedented in peacetime. Following the national leaflet drop, the television advertising campaign⁷⁰ and the establishment of a national Aids helpline, 'Aids Week' (Davies, 1993, pp. 28-30) offered 19 hours of public broadcasting TV time devoted entirely to Aids, and began the process of mainstreaming Aids in the public imagination. Aids Week and the use of television also represents the primacy of a liberal approach to public health that won out as government policy over more proscriptive or morally conservative approaches that had been considered (Berridge, 1996, pp. 112-115, 128-133).⁷¹

⁶⁹ In the USA, following cases of Aids being identified beyond gay men only in 1982, an alternative version of the this 'othering' which creates a psychologically protective distance between the general population and minority groups in society was termed 'the 4 H' groups by the media: heroin addicts (injecting drug users); haemophiliacs; Haitians and homosexuals (Harden, 2012, p.31).

⁷⁰ See footnote 60.

⁷¹ By liberal I mean approaches that accepted and were based upon the need for accurate information to be provided to the whole population and sought to present the issues as medical matters related to health and wellbeing without moral judgments being made. By contrast by proscriptive or morally conservative I mean those approaches that understood Aids as a moral crisis before a national health emergency and the arguments that providing accurate information especially about sexual practices and drug use would be a corrupting moral influence.

It was not until the realisation that it was not only the sexual practices of 'deviant others' but sex itself that posed a threat to the mainstream population that efforts to combat Aids took centre stage.

Whether we consider the governmental, societal, media, medical or individual level responses, it is simple to understand this journey from inaction, lack of concern and denial, to engagement and action, as one determined by distance and proximity. The greater the distance between us and danger, the safer we remain, and the less motivation we have to act. The greater the proximity, the more affected I feel, and the more urgent thought and action becomes. In some senses it is that simple. Things become more complicated after we perceive the need to take action. It is then that we must decide on what constitutes the threat, and what action should be taken to mitigate risk and minimise harm. Throughout the story of HIV and Aids so far we can see that there have been competing understandings of what we are threatened by, and it has been differing perceptions of the nature of what threatens us that has determined our action or inaction.

1.6 Contextualising HIV historically

To risk summing up this very brief snapshot of the societal and governmental responses I argue the following:

- The earliest years of Aids and HIV were characterised by an initial reluctance to accept or inability to foresee the extent of the problem that was emerging. Governmental agencies were slow to react. This can be understood as a period marked by denial.
- As HIV and Aids moved beyond definition as a 'gay plague' and was perceived as a potential threat to the general population, governmental and community resources were mobilised for both care and prevention. There was a high level of fear of HIV and Aids in society as the government, media and community groups mobilised in a kind of wartime emergency response.
- From the outset it was ordinary people who took action first. As members of the communities most directly impacted, gay men initiated support for those infected, and became the campaigners who pressed for a more adequate response from governments and society.

- In the nineties public health campaigns, the media, and celebrity led events raised awareness and informed the general public with more accurate information. HIV prevention and education became a topic for discussion in public broadcasting, defying previous taboos in regard to issues of sex and sexuality. At the local level a variety of HIV support agencies existed in all major cities in the UK, and all regions. Stigmatising attitudes were challenged and changed, but HIV stigma and discrimination persists with detrimental effects on the health and wellbeing of any person diagnosed (Dodds, 2004; UNAIDS 2007; Carter, 2008; Rueda et al. 2016).
- Tensions between those who held conservative moralistic views and community activists and health education specialists persisted. The meaning of Aids and the measures taken to address the crisis were debated and remain controversial, although a liberal health policy was eventually implemented in the UK.
- Since the introduction of ARV therapies in the mid-nineties the HIV pandemic has been controlled to some extent. The worst case epidemiological predictions of HIV in the UK were averted via public health campaigns and deaths from Aids have declined dramatically. Today, for those with access to treatment HIV⁷² can be understood as a long term manageable health condition rather than the fatal illness leading inevitably to Aids which it once was.

1.7 Contextualising HIV in contemporary society

Having revisited the story of how HIV impacted British society historically, I conclude this section with an update of key developments and a brief description of the context today and how it differs from that described above.

First, the epidemiological data and medical prognosis are relevant. In the UK today there are an estimated 102,000 people living with HIV, of whom 7,800 are unaware of their infection.

⁷² This statement relies upon the availability of treatment. Within the global context it should not be presumed that treatment is universally available. Progress towards the UNAIDS '90:90:90' global targets set in 2014 to achieve 90% of all people living with HIV: knowing their HIV status; receiving treatment; and having an undetectable viral load; by 2020, is faltering. In 2017, of the estimated 36.9 million people living with HIV globally 59% were on treatment and 47% had suppressed viral loads (UNAIDS, 2018a). Discussion of the global pandemic is beyond the scope of this study, however there are obvious implications for any immigrant in the UK who is diagnosed with HIV.

In contrast to the eighties when HIV emerged as a disease amongst young gay men, and latterly as affecting black Africans those diagnosed today are a more diverse group:

- Over one third are aged fifty or older.
- 48,900 are gay and bisexual men of whom 14% are from BAME groups.
- Approximately half of all those accessing treatment are heterosexual of whom over one quarter are white.
- Over half of people receiving HIV specialist care are white, and almost a third are black African.
- The two most disproportionately affected communities remain gay men and black Africans.⁷³
- Just under half of all people receive treatment in London and just over half of all those diagnosed are living in other regions (PHE, 2018; Nash et al. 2018 a).

The good news is that for the first time in 2017 rates of new diagnosis fell across every affected population group with 4363 people diagnosed during 2017 compared to 6043 in 2015 (PHE, 2017). This is due in large part to the effectiveness of treatment in two distinct but related ways. First, in 2017 98% of people receiving care were on antiretroviral treatment of whom 97% had an undetectable viral load.⁷⁴ Building on previous research the 'Partner 1' and 'Partner 2' studies have shown that a person living with HIV cannot pass on HIV with an undetectable viral load (Rodger, et al. 2016; 2018). Ironically, this means that anyone infected with HIV receiving virally suppressant treatment represents a safer sexual encounter in terms of HIV transmission, than someone who has not had a sexual health check-up since the last time they had sexual intercourse. Effective viral suppression undoubtedly accounts for a significant fall in the rates of new diagnosis. Second, the increased use of pre-exposure prophylaxis (PrEP) by sexually active gay men, either through involvement in clinical trials in England (McCormack, 2016), or via independent purchase

⁷³ Black African communities and gay men remain the two most affected groups: 1 in 17 men who have sex with men in the UK are HIV positive, and this rises to 1 in 7 gay men in London. 1 in 23 black African women and 1 in 45 black African men are living with HIV infection. Black Africans represent 1.8% of the UK population but 34% of all people diagnosed with HIV (NAT, 2014a).

⁷⁴ Clinical outcome measures were high across all groups, although virological suppression was slightly lower among 15-24 year olds (87%) which indicates that for some young adults ARV adherence is inconsistent.

online, has also been shown to be highly effective in reducing risk of HIV transmission (Collins, 2018; 2019; Brady, 2019). Therefore people successfully receiving HIV treatment in this country no longer pose a threat of onward transmission of the virus to others. A person diagnosed with HIV in the UK today receiving treatment can expect to live a relatively normal life (Trickey, et al. 2017). However this statement requires the qualifications that follow below.⁷⁵

Second, the current availability of support services in society for those diagnosed needs to be considered. Increased expenditure on ARV medication, a reorganisation of clinical and HIV prevention services within the NHS⁷⁶ designed to ‘mainstream’ HIV care within the wider NHS provision, (partly as a cost effectiveness measure and partly justified by a drive to ‘normalise’ HIV infection as a medical condition like any other), and the government policy of ‘Austerity’ has had a massive negative impact on the provision of specialist support services for people diagnosed with HIV (Dalton, 2016; NAT, 2017). Many of the community organisations that received funding for care and support have closed or merged since the beginning of the new century.⁷⁷ The network of available specialist HIV support services has reduced dramatically (NAT 2017a; BHIVA, 2019). Although medication has vastly improved the prognosis for someone living with HIV, in the UK today people are much less effectively supported than they were in 1995 or 2005.

⁷⁵ HIV remains a condition without a cure. However scientific research is making progress. The first successful stem cell transplant occurred in the so called ‘Berlin Patient’ in 2008 – Timothy Ray Brown who had Aids remains free of HIV in his body today. Results of stem cell transplant in the second and third cases, the so called ‘London Patient’ and ‘Dusseldorf Patient’ have been made public in 2019. 18 months after the procedure HIV is undetectable in the London Patient. However, in both later cases it is too soon to judge the transplants to have effected a cure. Secondly, the treatment is complex depending on expensive and risky medical procedures and reliant upon donors who have a particular genetic mutation of receptor genes (Mack, 2019).

⁷⁶ Changes made within the Health and Social Care Act 2012, have resulted in a very complex commissioning landscape, resulting in the fragmentation and destabilisation of HIV services, and reduced provision of social and community support services (APPG, 2016). Following these changes CAPS income for services commissioned by local government to provide peer support in London fell from £12k annually to £4k. In England there was an estimated 28% decrease in expenditure on HIV support services between 2015/16 and 2016/17 (NAT, 2017b).

⁷⁷ For example services provided by The Landmark centre in Lambeth mentioned above was merged with THT in 2001 and the centre closed in 2002. The Positive Parents and Children HIV Charity (PPC) merged into the larger METRO charity in 2017. The London Ecumenical AIDS Trust (LEAT) closed due to lack of funding in 2014. The London Lighthouse closed in 2015.

Third, public health campaigns to promote HIV testing have impacted upon how living with HIV is perceived within the UK. Given that successful treatment adherence means that an HIV positive person cannot transmit HIV, testing has been promoted within the general population (NICE, 2016). Early diagnosis and treatment obviously reduces the number of new infections within the population, and each person not infected who otherwise might have been, represents a saving to the NHS of an estimated £360,000 lifetime treatment costs (NAT, 2017a).

However, stigma persists in society today (FPA, 2015; Owuor & Nake, 2015; NAT, 2014; 2017) which leads to complacency and/or denial. Anxiety about a positive test result and the belief that HIV is something that affects 'others' means that many people who are infected do not get tested.⁷⁸ The number of late diagnosis in 2017, comprising 43% of all new diagnosis, and 50% and 57% of all new diagnosis of heterosexual women and men respectively attests to this fact (Nash et al. 2018a).⁷⁹ To encourage HIV testing, public health campaigns, for example the national HIV testing week, have presented a simple message. Reinforced by promotional images of happy healthy smiling people⁸⁰ HIV as a 'manageable condition' and as 'just a virus' like any other virus, have constituted the key health education messages since the introduction of anti-retroviral therapies, for two related reasons.⁸¹ Firstly the 'manageable' label is intended to reduce the fear and anxiety, still associated with HIV, so that more people will access HIV testing and those who need treatment will receive it before the onset of Aids. Secondly, the drive to 'normalise' HIV as a medical condition like any other, which can impact on all groups in society - sometimes also referred to as 'de-gaying HIV' or presenting HIV as 'an equal opportunities virus' - is an

⁷⁸ The numbers of heterosexual men and women who attend sexual health clinics in England, who decline HIV tests is increasing (Nash, 2017).

⁷⁹ Late diagnosis reduces the effectiveness of treatment and carries a ten-fold increased risk of death within 1 year compared with those diagnosed early. Diagnosis is considered late when the immune system 'CD4 cell count' is below 350/ml. A CD4 count below 200/ml has been used to define progression from HIV infection to AIDS. In HIV negative healthy adults the CD4 count will be in the range 500 – 1600/ml.

⁸⁰ See for example <https://www.hivpreventionengland.org.uk/campaigns/national-hiv-testing-week/> [Accessed March 2019]

⁸¹ I am summarising the variety of approaches to health promotion and simplifying the messaging which is usually presented with more clinical language and detail. For example, these two messages are inherent in the NAZ Project 'Testing Faith' HIV community testing campaign aimed at faith leaders in England. My main concern here is with how the issues around HIV are communicated for and to the general public.

attempt not only to normalise HIV testing, but also intends to reduce the general and various kinds of HIV stigma (Baldwin, 2006, pp. 197-201; Nicholls, 2017).⁸²

Fourth, the socio-economic profile should be understood. Poverty, unemployment and social inequality are significantly higher among people with HIV than the general population. A third of people living with HIV in the UK live in poverty (NAT, 2017; NAT 2018c); economic hardship is particularly pronounced for black and ethnic minority people and women (FPA, 2015).⁸³ Government policy in regard to immigration and asylum is one of the main causes of poverty and destitution for people living with HIV (NAT, 2011; Rosenfeld et al. 2019, p.265) and amongst older people one survey found that 58% of survey respondents were defined as living on or below the poverty line (THT, 2017).

Fifth, notwithstanding advances in treatment and increased life expectancy, the best physiological outcomes require early rather than late diagnosis and strict adherence to medication. Research shows that intravenous drug users and young adults often fail to meet this second requirement (Nash et al. 2018), and poor mental health negatively impacts adherence (Gonzalez et al. 2011). 230 people newly diagnosed with HIV in 2017 also received an Aids diagnosis (PHE, 2018a).

Sixth, although mother to child transmission has been nearly eliminated within the UK,⁸⁴ children and young people are also living with HIV. Since 2008 cumulatively, 963 children have been born infected with HIV in England and Wales. 356 children under 15 years and 2349 young adults age 15-24 years were seen for HIV care in the UK in 2017 (PHE, 2018a). These children and their families face particular challenges, not least because young adults

⁸² The reasons for the so called 'de-gaying' of HIV in public health messaging are too many to go into here. There is also a historical context that space does not allow me to describe in any detail. Suffice to say that the 'de-gaying' 'normalising' or 'generalising' of HIV did not first begin in the era of ARVs. As a public policy approach it also refers not only to public health campaigns but also to the allocation of resources and political choices made in order to minimise possible hostile reactions from the general public towards minority groups i.e. gay men; IV drug users; and black Africans. The first time HIV and Aids was 'generalised', for different reasons to those given here, was during the 1986-1987 national AIDS campaigns. The allocation of resources for increased HIV testing is not uncontroversial. Writing in 2000 for example, McGarrigle and Gill argue that increased HIV testing will misdirect resources and attention from the communities most affected by HIV (McGarrigle and Gill, 2000).

⁸³ In this national survey one third of participants stated they had gone without food and/or struggled to keep up with financial commitments in the previous 12 months (FPA 2015, p.12).

⁸⁴ Of 486 children born to HIV positive women in 2017 only 1 child received an HIV positive diagnosis.

living with HIV will be an increasingly isolated group as the numbers of new infections in children diminishes.

Seventh, as noted over one third of people receiving treatment are over fifty years of age, estimated to rise to over half of all people living with HIV by 2028 (Rosenfeld et al. 2019, p.259). Like their younger counterparts older people reflect the diversity of those living with HIV. Their experience is novel being the first generation to age with HIV: “an historical fact introducing a mix of unique challenges” (Rosenfeld et al. 2019, p.260). Scientific research has yet to discover what the effects of living with HIV over the longer term are, although early indications suggest that people living with HIV will suffer higher rates of comorbidity and earlier death than in the general population.⁸⁵ People living with HIV may experience a multitude of related health conditions often earlier in life than their HIV negative peers (Power et al. 2010). HIV ‘ages’ people more rapidly and the chances of many other long-term and life threatening health conditions are significantly higher than for a non-HIV infected person. And, these older people often exist within fragile social networks; for example older gay men, so-called ‘long-term survivors’ who were diagnosed before 1996,⁸⁶ have come through all that I have described above, have lost friends in the past and more recently to HIV and Aids, are often dependant on benefits and have been long term unemployed (THT, 2017; Rosenfeld et al. 2019, p.260). Similarly, the migrant who has been dependent upon the UK asylum system will have endured long periods of enforced unemployment and have few networks of support.⁸⁷ In a national survey 72% of all people living with HIV had at least one other diagnosed long-term health condition. This equates to over 60,000 people managing HIV plus another long-term condition every day. In addition to these physical health concerns, mental health problems were reported by half of people living with HIV, which is twice the rate of the general public (NAT, 2018c), and amongst

⁸⁵ Comorbidity includes: premature onset of cardiovascular disease; diabetes; bone and joint disorders; hypertension; kidney disease; peripheral neuropathy; dementia and other neuro-cognitive impairments.

⁸⁶ It is incorrect to assume that all diagnosed people over 50 years are ‘long term survivors’. Many new diagnosis amongst the over 50s especially within the heterosexual population are post 2000. For example, in 2017 in the UK there were 728 people newly diagnosed aged 50-64 years and 145 aged 65 years and older (PHE 2018a).

⁸⁷ See NAT <https://www.nat.org.uk/blog/3-ways-uk-asylum-system-fails-people-living-hiv> [Accessed March 2019]

older people a third are socially isolated and 82% experienced moderate to high levels of loneliness (THT, 2017).

Lastly, it is particularly relevant in this study to note that 70% of people living with HIV are religious or spiritual, and 49% say their religion is very or fairly important to them. 52% of all people living with HIV identify as Christian. However, of those who say their faith is important, 18% had not shared their HIV status with anyone, which is a higher rate compared with those who said faith was not important where non-disclosure ran at 10% (Nash et al. 2018). A 2015 national survey reported that only one in four people who were active members of a faith community had revealed their HIV status to anyone within their religious group; and of those only 57% reported feeling supported, which suggests that the remaining 43% did not feel supported (FPA, 2015).

1.8 Summarising the current context in historical perspective

I want to argue for four key points which are important for the argument that follows. First, this historical context reminds us of how HIV and Aids provoked a national crisis in the 1980s. The terror of Aids impacted at the individual and societal level. What Berridge has properly called the 'war years' saw a governmental response and a national public health campaign unparalleled since the second world war. When HIV and Aids impacted in a family, in a community or parish, this sense of being in the midst of war was experienced amongst friends. This appreciation of the impact of HIV and Aids as a subjectively experienced trauma, often played out in families as a kind of tragic but secretive drama, is important for this study. Anyone diagnosed in the eighties or nineties carries this history with them. For all my informants whether their encounters with HIV occurred during the so called war years or later, the experience is often referred to in just these terms. In chapters three and four my interviewees and I will use the phrase 'war years' in relation to these kinds of experience.

Secondly, although progress has been made in reducing ignorance about HIV, for example about the ways in which HIV can or cannot be transmitted, the fears, prejudices and human tendency to distance one-self from HIV remain evident in our society. HIV stigma as something both internally felt and enacted externally, is stubbornly persistent. Again, stigma will be revisited in my interviews, and will be central for the theological understanding of

the experience of living with HIV which I put forward in Part II. As Gideon Byamugisha⁸⁸ has observed: “It is now common knowledge that in HIV/AIDS it is not the condition itself that hurts most...but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV-positive people have to deal with.” (Paterson, 2009, p.6). This is as true within a UK context as it is in other parts of the world with higher rates of HIV incidence and greater extremes of poverty.

Third, I argue that taken together the advances in medical treatment and public health campaigns have led to a public perception that HIV is no longer the exceptional condition that it was once considered to be. I wonder if there are unintended effects that actually further disadvantage people living with HIV and, rather than reducing or eliminating HIV stigma, add to it? Allan Brandt made a similar point: “Routinization [of HIV and Aids] has the effect of distancing the public from the suffering inherent in the epidemic. This act of social dissociation, the idea that AIDS is mundane, further marginalizes those who are ill.” (John Gagnon quoted in Brandt, 1995, p.129).⁸⁹ The ‘HIV as manageable’ message reduces living with HIV to a medical condition and results in a diminishing concern to address the social, psychological and spiritual needs of those who are diagnosed. In public perception ‘HIV is over’: “Without question great progress has been made in the treatment of HIV, however this has led to society at large acting like it’s old news - people don’t want to talk about it anymore. This included me, until in February 2016 aged 63 I was diagnosed as HIV positive” (NAT, 2017, p.7). In chapter six I will argue that popular misunderstanding is a contributory factor in erecting barriers to authentic encounter between those who are and those who are not diagnosed.

Fourth, the evidence above demonstrates that people living with HIV in the UK today, as a group, are multiply disadvantaged when compared to the general population. Rosenfeld

⁸⁸ Revd. Gideon Byamugisha is a founder member of the African Network of Religious Leaders Living with and Personally Affected by HIV and AIDS (ANERELA+). He was the first ordained African minister to publicly disclose his HIV positive status in 1992. He is also a contributor to CAPS *Positive Faith* project. See Films in bibliography.

⁸⁹ Writing in 1995 Brandt observes this process within the USA context. He also notes how this impacts on public policy and services delivery, and quoting John Gagnon predicts that in the USA Aids will be treated as an “affordable pandemic which involves tolerable levels of wastage” because it impacts primarily within socially marginalized groups such as gay men, African and Latino-Americans, intravenous drug users, their female sexual partners and their children, whose illness and deaths are tolerated by “the many and the powerful.” (Brandt, 1995, p. 130). The prevalence of HIV infection in the USA today, especially within the African and Latin American demographic, lends credence to the prediction. See HIV.GOV USA government website.

(2019), drawing upon Fraser (2003) argues that the core experience of older people living with HIV and their social position, are shaped by both the economic structure and the “status order of society” (Fraser, 2003, p.15 quoted in Rosenfeld, 2019, p.261). Using Fraser’s three domains of inequality: a) *recognition* - social status, cultural visibility and cultural worth; b) *resources* - economic, social care and support; and c) *representation* - social and political participation and access to justice (Rosenfeld, p.261), research participants identify the fears and judgmental attitudes that constitute HIV stigma generally, in combination with ageism in society, as the forces behind their low social worth (Rosenfeld, pp.262-265). In terms of access to resources: interrupted work histories due to ill health and/or migration; recent changes to the welfare system; and immigration status; are factors that keep them financially poor, act as barriers to employment, and inflict a psychological cost because of the insecurity and instability inherent in these conditions (Rosenfeld, pp.265-268). The social support provided within a HIV peer support setting where they did not feel judged, was essential, in “stark contrast to the awkwardness, hostility or misunderstanding participants expected to experience in non-HIV-dedicated spaces should their HIV be known” (Rosenfeld, p.268). In terms of representation, in which I would include the capacity to advocate for oneself, welfare changes and an increasingly punitive government policy in regard to eligibility; concerns about growing older and encountering HIV-related stigma and homophobia in long-term care settings; are some of the factors that threatened Rosenfeld’s subjects’ capacity to participate in wider society, alongside the defunding of HIV service organisations, which removes their access to advice, advocacy and justice (Rosenfeld, pp. 268-271).⁹⁰

Rosenfeld’s study and the evidence provided above shows that whilst HIV is a core aspect of identity for anyone diagnosed, the drivers of exclusion, disadvantage and injustice impact a person according to their stage in life, personal history and social and economic circumstances. Within the diverse population of people living with HIV stigma remains a significant factor that problematizes relationships, and adds complexity in often already challenging situations. Many people living with HIV in the UK today are disadvantaged

⁹⁰ Dr. Dana Rosenfeld is a member of the ‘HIV and Later Life’ research team based at Keele University. Her co-authors are Professor Damien Ridge (Westminster University) and Dr. Jose Catalan (Chelsea & Westminster University Hospital). See <https://www.keele.ac.uk/csg/research/hivandlaterlife/> [Accessed March 2019].

because of the structural economic and political forces of immigration policy or enforced poverty; a majority are also members of minority groups subjected to the oppressive cultural forces of racism, homophobia, xenophobia and disdain for the poor. These are the people from whom support services are being withdrawn, and as will become evident, the people ignored by the contemporary church. In light of all the evidence of marginalisation and disadvantage as I have argued elsewhere, the proposition that HIV is manageable, should always be followed by the question: manageable for whom? (Manning, 2016).

Having described the historical context of HIV in British society, and providing some factual detail for the contemporary medical and social reality that affects those diagnosed, I now turn in the following chapter to a consideration of how Christians and the Church have responded historically, and are responding to HIV in society today.

Chapter 2. Historical context: Considering HIV in the Church then and now

2.1 Introduction

Christian responses within the UK is the focus of this chapter. I will present the historical theological and ecclesial landscape within which this inquiry is set. A complete study of the churches pastoral and theological response to the HIV pandemic within the UK is beyond the scope of this thesis, however, given that there is no published history of ecclesial responses within the UK, and in the social science literature mention of churches or individual Christian leaders is sporadic and often negative, I will use this opportunity to make an original contribution to public knowledge. Approaching the fortieth anniversary of the 'time of Aids' there is an increase in interest in academia to document the past.⁹¹ This chapter will document some of the faith-based 'activism' that is more usually overlooked, and place on record historic and contemporary Christian responses to HIV. As with the previous chapter, it is relevant for the argument that I make later to be reminded of the historical and current ecclesial context. I will show that the first Christian responses to HIV in our society came from individuals. More organised pastoral responses did not emerge until the end of the first decade. I will argue that responses from the Institutional Church when they did come were mostly tentative, partial and reticent. From the evidence offered in this chapter I argue that since the introduction of more effective medicines in the late nineties in

⁹¹ For example 'Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health' (EUROPACH) is a Humanities in the European Research Area (HERA) funded project under the auspice of a collaborative network of universities in the UK (Goldsmiths, University of London), Germany (Humboldt University), Poland (Jagiellonian University) and Switzerland (University of Basel). It is concerned with the ways in which the histories of HIV are mobilised in current policy and activism. Alongside a number of other outputs, the project will result in the establishment of a European Archive of HIV, which will include video-recorded interviews with people who have been involved in HIV policy and activism throughout the course of the epidemic. I was interviewed by Dr. Emily Jay Nicholls in 2018 for this research and introduced her to CAPS members, including Fr. John White, who were also interviewed. In correspondence for CAPS News 2018, Dr. Nicholls wrote: "After speaking with CAPS Chair Vincent Manning, and other activists...he kindly put me in touch with, it became clear that including accounts of the Catholic response to HIV in the archive would be important in order to ensure that these histories were available to researchers in the future. In many accounts of the history of HIV, there is little mention of the work of faith groups and where they are mentioned, this is rarely in a manner which is reflective of the kinds of support and activity which I have had the privilege of hearing about during the course of the research. There is clearly much that can be learned from the experiences of people involved in church based activism." See CAPS News 2018 & <http://europach.phils.uj.edu.pl/> [Accessed April 2019]. Similarly, the London Metropolitan Archive is collaborating with the National HIV Story Trust to construct a video archive documenting the story of HIV and Aids in this country. See <https://news.cityoflondon.gov.uk/lma-welcomes-largest-ever-hivaids-video-archive-at-launch-of-national-hiv-story-trust/> and <https://www.nhst.org.uk/> [Accessed April 2019].

high income nations, the Church has disengaged with HIV and Aids both pastorally and theologically, as a concrete social and personal reality *in our midst*. Consequently, the reality of living with HIV is not understood because Christians living with HIV are unseen and unheard.

2.2 Christian responses to a global pandemic and public perception

There is no published historical study of the Christian churches' responses to HIV and Aids in the UK. More has been written about the history of Aids within the US context including the churches' responses (Kowalewski, 1994; Petro, 2015).⁹² When Christianity is mentioned in the few historical treatments of HIV and Aids in the UK (Garfield, 1995, pp.160-171; Berridge, 1996, pp.135-137), or in a US context (Engel, 2006, pp.120-124; Harden, 2012, pp. 118, 208), it is at best neutral, rarely complimentary and more often critical.

The first responses of the churches in the UK were muted. Prior to 1986, I can say that no response was the official response in the UK (Pattison, 1990, p.9; Berridge, 1996, p.137). In this sense the gradual awakening to the pandemic as a serious public health emergency within the church paralleled that of the government and wider society. In the years 1981 – 1986 whilst Aids confronted individuals and families, institutional-pastoral or formal theological responses were absent. For most people, information about the Christian response, like the medical and social understanding (and misunderstanding) of this frightening new disease came via the media.

As developments within the USA influenced the political and cultural responses here, so too the first Christian voices heard in the early years of the pandemic came from a US context. Amongst the most frequently cited are Cardinal John O'Connor of New York⁹³ and Rev. Jerry

⁹² At time of the publication *'All Things to All People: The Catholic Church Confronts the AIDS Crisis'* Mark Kowalewski was a postdoctoral fellow at the Drug Abuse Research Center at University of California Los Angeles. His work (1994, pp.45-60) provides a useful analysis of the Catholic North American bishops' official responses to HIV (USCCB, 1987, 1990). Anthony Petro is assistant Professor of Religion at Boston University. In *'After the Wrath of God: AIDS, Sexuality, & American Religion'* pp.115-136 he also provides a full account of the controversy that surrounded the American bishop's statements, for example, in regard to information on condoms as a part of HIV prevention and education, allowed for in the 1987 document and disallowed in the 1990 statement. The Catholic bishops of England and Wales never issued an official agreed statement in respect of HIV. Again, Hierarchical statements and documents issued elsewhere also impacted upon perceptions of the Catholic Church's involvement here, and reflect tensions in the Church generally, which will be discussed in this chapter.

⁹³ Cardinal O'Connor gave the opening address at the first conference on Aids held at the Vatican in 1989 (O'Connor, 1989). For a comprehensive account of O'Connor's political and public stance see Petro, 2015.

Falwell, leader of the 'Moral Majority' fundamentalist political organisation.⁹⁴ O'Connor came to represent the loudest Catholic voice whose main concern seemed to be to uphold the Church's prohibition on the use of condoms and to protect wider society from the morally corrupting influences of both gay sexuality and sexual health education. Being a member of President Reagan's Commission on AIDS, and with St. Vincent's Catholic hospital⁹⁵ in New York being one of the first providers of clinical and in-patient care for gay men with Aids, he attracted media attention when he insisted upon an opt-out from the US government's requirement that health care providers offer counselling on 'safer sex' methods, including the use of condoms (Jonsen and Stryker, 1993, p.293). Ridiculing educational literature and techniques that public health authorities endorsed for preventing the spread of HIV, in somewhat inflammatory language which misrepresents the Health education campaigns and techniques of the time, O'Connor said: "In order to get AIDS money to facilities run by nuns, they will have to teach the residents there to masturbate and also show them obscene films." (Allen, 2002, pp. 144-145).⁹⁶ O'Connor became a hate figure for the Aids activists demonstrating for a more proactive response from the US government. Members of 'Act Up'⁹⁷ staged a 'die-in' in St. Patrick's Cathedral in protest against all that he represented (Jonsen and Stryker, 1993, p.119; Kramer, 1995, pp. 191-192; Cohen, 1998, pp. 20-22; Allen, 2002, pp. 142-143; Gould, 2009, pp. 285-286). In defence of his position when criticised, O'Connor hit back: "Don't blame the Church if people get a disease because they violate Church teaching" (Allen, 2002, p.143). Blaming Homosexuality for Aids, Falwell said on National Television: "a god who hates sin has stopped (homosexuality) dead in its tracks by saying 'do it and die. Do it and die'" (Murphy, 1988; Jonsen and Stryker, 1993, p.131; Allen, 2002, p.121). And, "Aids is a lethal judgement of God on the sin of homosexuality (and) on America...He is again bringing judgement against this

⁹⁴ Falwell and O'Connor were making public statements and influencing public policy in the USA from as early as 1983. (Shilts, 1998, pp.347-348).

⁹⁵ For a short account of how the St. Vincent's 'Supportive Care Program' began see Berrigan, 1989, pp.xi-xv.

⁹⁶ O'Connor also objected to a clean needle exchange policy being implemented in New York to minimise risks of infection amongst IV drug users, accusing the city of "dragging down the standards of all society." (Berridge & Strong, 2002, p.164; Harden, 2012, pp. 117-118).

⁹⁷ See footnote 55. See also a report of a later ACT UP Protest in Boston Cathedral, Dawson, 1990.

wicked practice through Aids.” (Allen, 2002, p.123).⁹⁸ Their voices were heard in the UK⁹⁹ and their underlying message added to by others who claimed to speak in the name of the church. James Anderton, a former Methodist lay preacher who converted to Roman Catholicism, made national headlines when as Chief Constable of Greater Manchester in 1986, he described people with Aids as “swirling around in a cesspool of their own making”. Interviewed later on BBC Radio Four he claimed that God was speaking through him. (Garfield, 1995, pp. 113, 123-124; Berridge, 1996, pp. 109, 137). Member of Parliament Edwina Currie put things succinctly: “good Christians will not catch Aids” (Alton, 1987). The first and ‘loudest’ Christian voices to be noticed here in the UK and around the world were condemnatory and judgmental. The message was that Aids was the result of sinful behaviour. It was as simple as that.

In the mid-eighties there was a rise in negative attitudes towards gay people in the UK (Berridge, 1996, p.132). Kenneth Leech (1990, p.61) quoting Sara Diamond, links this to branches of the church in unambiguous language: “The recent resurgence of homophobia is clearly connected with both crude right-wing fundamentalism and with developments akin to a kind of creeping fascism within the Christian world. In both the USA and Britain, it is right to warn that ‘in the age of AIDS, gay and lesbian people remain the most vulnerable targets of Christian Right venom, which is likely to spread along with the epidemic.’”

Mainstream Church leaders here did not come under attack as O’Connor had in the USA. In large part this was because unlike Falwell and O’Connor they remained mostly quiet, in public (Pendergast, 1990, p.351). When institutional responses were formulated in 1987,

⁹⁸ Falwell’s Moral Majority opposed governmentally funded research to find a cure for AIDS because the disease was a gay problem (Jonsen and Stryker, 1993, p. 131).

⁹⁹ That figures like O’Connor and Falwell dominated media coverage in the USA belies the diversity of other more compassionate Christian leaders’ statements and more constructive responses. For example Archbishop Quinn of San Francisco, which like New York was an epicentre of HIV due to a large gay community, writing in *America Magazine* said: “We must support those who face this terrible and perplexing sickness in every possible way by our presence of concern and love, by spiritual guidance, by the sacrament of light of the Church, and by counselling the bereaved, and by cleaning and anointing the diseased.” (Milliken and Stearns, 1988, p.41). Also in San Francisco parishioners of the Most Holy Redeemer Catholic Church in the Castro district, set up the AIDS Support group in 1985 which provided pastoral and practical support for people with Aids (Mena, 2015). The first interfaith conference on Aids in the USA, took place in San Francisco, attended by more than 500 clergy and other care-givers, in March 1987 (Milliken and Stearns, 1988). One of the first conferences addressing Aids anywhere in the world was granted additional public legitimacy and respectability by Cardinal Terence Cooke, O’Connor’s predecessor, who opened the conference in New York in 1983 (Petro, 2015, p.108).

the condemnatory tone was softened with calls to compassion, and the Anglican and Roman Catholic Churches in England gave qualified support to a liberal approach to public health, including on matters of sexual health education (Berridge, 1996, pp. 135-137).¹⁰⁰ Both Cardinal Hume (1923-1999) (Hume, 1987, 1987a) and the Anglican Church argued that Aids should be understood as signifying a moral crisis in society as much as a medical one. Christians should 'love the sinner whilst hating the sin' (Berridge, p.136) and a 'return' to traditional Christian teaching on sexual morality was needed (Hume, 1987, 1987a; Habgood, 1987; Berridge, 1996, pp. 135, 145). Whilst Hume and the Archbishop of Canterbury Robert Runcie (1921-2000) did not endorse the approach, they did not publicly denounce the government's policies. Neither did the Anglican, Roman Catholic or Free Church leadership respond to the government's invitation to collaborate strategically at a national level (Berridge, 1996, pp. 135, 137).

As in the USA, simplistic and theologically dubious statements, the more muted Church leader's responses here, and a lack of coordinated pastoral action led many to conclude that the Christian Church in general was unsympathetic to those directly affected or infected by HIV and Aids, and hostile towards HIV prevention efforts (Cosstick, 1987, p.48; Pattison,

¹⁰⁰ This cooperative stance with government ministers and departments should be appreciated in contrast with other lobbying that called for more extreme measures. For example in written submissions to the Social Services Committee on Problems associated with AIDS, which convened in 1986-1987 in the House of Commons, the Conservative Family Campaign amongst other recommendations called for: Aids to be a notifiable disease; mandatory testing of all visitors to the UK from Africa; The Christian Hospice movement be designated as the main providers of isolation wards for people with Aids; repeal of the 1967 Sexual Offences Act & the re-criminalisation of homosexuality; no provision of clean needles for IV drug users; contraceptives (condoms) to be made available for married couples only and the NHS to adopt a policy promoting chastity before marriage and faithfulness within marriage; the value of marriage be taught in schools along with the illegality of homosexuality and homosexuality as a public health risk; government funding to be withdrawn from the Terrence Higgins Trust and the Family Planning Association because they promote homosexuality and encourage ideas incompatible with morality and encourage promiscuity respectively; funding should be diverted to Christian counselling services to help homosexuals refrain from their practices. Their submission also includes the assertion that Aids may be contracted through contact with an infected person's skin, bare feet and kissing, and they roundly denounce the 1987 media campaign as distasteful, offensive and counter-productive. The key to an effective response to Aids, they assert is "whether the Government is prepared to make a moral stand on what is essentially a disease spread by immoral behaviour." (Clarke and Potts, 1988, pp.270-274). Whilst these suggestions may seem outrageous, measures such as these were considered seriously at the time by politicians, and had significant popular support within the general population. For example, powers of quarantine for infected people was considered by government ministers as late as 1992 (Berridge, 1996, p.254). Lewis (2002, pp.40-41) considers it probable that the impracticality of quarantine was a decisive factor against the implementation of such a policy. Berridge also notes that the law was changed in 1984 to allow the compulsory removal of a person with Aids to hospital, although this was only invoked in one case, in 1985. The ensuing protest ensured that this power was never used again (Baldwin, 2006, pp.58-59).

1990, pp. 11-12; Woodward, 1990, p.1; Jonsen and Stryker, 1993, p.119; Dixon, 2004, pp. 151-152). From the outset, in public perception, the first Christian responses reflected the Institutional Church's primary concern: to be clear about what was right and what was wrong (Cosstick and Radcliffe, 1987), rather than witnessing to compassion or concern for those directly affected. As I describe shortly, more thoughtful Christian responses were enacted during the eighties, and more thoughtful theological voices would be articulated in the nineteen nineties. However, it remains true to say that first impressions count, and the 'tone' of the Church's response to HIV and Aids was set in the first decade, and, rightly or wrongly, that negative impression remains hard to allay.

2.3 Public perception of the Christian 'stance' today

I suggest that in the UK, public perception of the Churches engagement with and attitudes to HIV remain generally negative today. The Catholic Church has been accused of promoting death because of continued opposition to the use of condoms (Alsan, 2006; Vitillo, 2012). The theological and internal ecclesial tensions exposed by HIV and Aids so dramatically in the eighties exist in all churches still, manifested variously, in the media. How the churches, especially the Roman Catholic Church, respond to HIV as a global phenomenon shapes how the churches stance is understood locally.

What is noticed, especially amongst people living with HIV and those active in the voluntary and medical sectors (Arie, 2005; Bove, 2009), are statements about condoms that make the headlines, arguing contrary to scientific evidence (Fuller and Keenan, 2000, pp. 34-35; Alsan, 2006; Charania, 2011; von Sadovszky, 2014; Krishnaratne, 2016; Pascual, 2016) that condom use is unhelpful in reducing the spread of new infections (Fuller and Keenan, 2000, pp. 24-25; Pollitt, 2003; Smith, 2004; Joshua, 2010; Benedict XVI, 2010, pp. 117-119, 193-194). The Vatican statement on 'The Pastoral Care of Homosexual Persons' (Cong. for the Doctrine of the Faith, 1986) insensitively issued at the height of the Aids crisis is remembered. Ongoing debate in the Anglican Church about gay sexuality is noticed (The Archbishop's Council, 2013), and when evangelical pastors and other Christian leaders collude to criminalise gay men in Africa (Evertz, 2010, p.21; Goldstein, 2012; McAlister, 2016) the negative judgment is not lost on gay people and their allies in the HIV sector. The voices of Christians are heard in opposition to equality legislation, for example the repeal of Section 28 in 2003 and civil partnerships and gay marriage more recently. Efforts to educate young people have been

censored and educational materials withdrawn because the approach taken was considered too liberal by some members of the church (Owens, 2000).¹⁰¹ It is noticed when in pursuit of an ideologically 'pure' agenda, again in defiance of expert opinion and research evidence, a Catholic-Evangelical political alliance in the USA, influenced the distribution of global funds for care, support and HIV prevention, in favour of organisations that promote orthodox Christian views on marriage and sexuality, to detrimental effect upon HIV prevention efforts, and further marginalising vulnerable groups in society (Barnett and Whiteside, 2006, p.345; Evertz, 2010; Japah, 2013; McAlister, 2016).¹⁰²

Over the short historical course of the pandemic secular and medical approaches to HIV have, broadly, sought to provide accurate information within a 'harm reduction' framework; be inclusive and meet the needs of minority groups such as sex workers and gay men; and promote the technical means to both prevent and treat HIV infection, without attaching moral judgment. Although there remains a great deal more to do both in terms of access to treatment, and the prevention of new infections, and whilst the political commitment to 'end Aids' did not mobilise quickly enough (Barnett and Whiteside, 2006, p.5) the internationally coordinated efforts to combat HIV and Aids have, with this approach, achieved a remarkable degree of success in the last fifteen years (Byamugisha, 2010, p.15; UNAIDS, 2018a).

However, the Church has been confronted with the fact of millions of people, especially in countries where religious culture is more dominant than it is here, who evidently do not abide by the codes and restrictions imposed by traditional Christian (or other faiths) moral teaching (Defert, 1996). The Church has been challenged by the greater visibility of minority groups whose claim to equal rights has threatened the formal and informal regulation of wider social norms. In short, the pandemic has created a conflict between the values of a modern secular approach to the control of disease and traditional Christian morality. As I

¹⁰¹ See also CAL News no. 20 Feb. 1996.

¹⁰² Significant PEPFAR (US government) international funding was ring-fenced for organisations committed to promoting 'Abstinence' based HIV prevention and was directed away from organisations that included advice on family planning or access to abortion, for example. The Bush administration announced a new directive in 2005 specifying that "66 percent of resources dedicated to prevention of HIV from sexual transmission must be used for activities that encourage abstinence and fidelity," (Evertz, 2010, p.11). This led to American Christian organisations with little experience or track record in HIV prevention work being awarded millions of dollars to establish projects internationally (Evertz, 2010, p.21; Cahill & Urbano, 2010, p.19).

argued in the introduction and previous chapter, from the viewpoint of some Christians HIV education and prevention strategies represent further erosion of Christian standards in response to a pandemic which itself symbolises moral decline in a sick society. The often polarised arguments about: access to condoms; the proper boundaries of sexual health education; and the degree to which minority groups whose behaviour is deemed immoral and potentially corrupting by some, should be accommodated or included in wider society; were given loud voice when HIV first appeared and variations of these arguments have been amplified in the media ever since. As Petro and others have observed the pandemic “has helped draw the battle lines for the wider war over religion and sex” (Petro, 2015, p.2; Messer, 2004, pp. 23-24; Massingale, 2009, pp. 152-154). Debate within the church looks set to continue. What is undisputable is that the religious scrupulosity of many Church leaders, whether lay or ordained, inhibits effective prevention (as well as pastoral) work locally and globally (Keenan, 2000, pp. 15-16; Massingale, 2009, pp. 153-154) and I suggest this (along with all that I have mentioned) rather than the vast contribution of Christian agencies to care and prevention globally (Smith and McDonagh, 2003, p.3; UNAIDS, 2013) is the dominant fact when it comes to how the Christian churches stance is perceived still today, at least in the West, and especially amongst secular agencies and activists who are committed to defeating HIV and the attendant suffering.

2.4 Christian pastoral responses late eighties into the nineties

What religious leaders say is important. In public perception their words and actions often take prominence and ‘set a tone’. However, there is a plurality of belief and practice within all Christian traditions. From the beginning of HIV in the UK, unsympathetic and hostile religious tones have been counteracted within the context of pastoral ministry. Individual Christians have been willing to accompany people living with HIV and dying from Aids as a compassionate presence within this situation of suffering. The experience of Andrew from 1987 is an example: “The Church will be seen by how it acts, not by what it says...All the clergy I have met have treated me in a loving compassionate way. None of them have moralised. That has brought me closer to the Church. It confirmed my faith...But when the Churches condemn or judge us, they are damning us with the very thing that sustains us.” (Cosstick, 1987, p.46).

More credible and actually relevant Christian responses came from the many lay people, religious sisters and clergy, who became active volunteers in the voluntary sector organisations that proliferated in the eighties and nineties. Christians were to be found amongst the volunteers at THT, Body Positive, and The London Lighthouse (Pendergast, 1990).

As I described in the introductory chapter with an account of the Spode conference, from 1986 to 1990 there was an outbreak of alternative Christian responses pastorally and theologically. Some specifically Christian pastoral initiatives began.¹⁰³ Amongst these was CARA, founded in 1988 by David Randall, an Anglican priest who was living with HIV and died of Aids in 1996.¹⁰⁴ CARA soon developed as a support centre with similar aims to the Landmark and The Lighthouse providing a range of alternative therapies, counselling, group work and a network of supportive pastoral carers for people with Aids (Pendergast, 1990; Berridge, 1996, p. 136). In the first years CARA was populated by a small army of volunteer clergy and religious sisters (Walsh, 2000, pp. 19-20).¹⁰⁵ Also in 1988, Patrick Dixon, an Evangelical Christian founded ACET¹⁰⁶ providing home based support throughout London, and the Mildmay Mission Hospital, founded in 1866 as a Christian response to the outbreak of cholera amongst London's poor, discovered a new mission, opening a ward for people with Aids (Pendergast, 1990; Meadows, 2003).¹⁰⁷

In 1988 Catholic AIDS Link (CAL) was formed, coordinated jointly by volunteers Krystyna Fuchs, Martin Pendergast and Peter Harris, to offer 'non-judgemental, spiritual and practical support' to anyone affected by HIV and Aids.¹⁰⁸ The new organisation's patrons included Bishop Victor Guazzelli, the Duchess of Norfolk and Lord Tordoff, as well as medical and pastoral care experts. The first major event was a public Mass for World AIDS Day, 1st

¹⁰³ Source for data includes CAL Newsletters issued between 1989 and 1999 held at The Wellcome Library, Euston, London.

¹⁰⁴ Neither the founding of CAL nor the establishment of CARA should be understood as a response of the Institutional Church. Randall was viewed with suspicion within his own church and received no funding from the Church of England. CAL was formed when the founders realised that, despite requests that they do so, the Catholic Bishops were incapable of organising a more formal pastoral ministry (Pendergast, 1990; Randall, 1994)

¹⁰⁵ See also History at <http://caralife.com/> & CAL News no. 5, June 1990 & Randall, 1994.

¹⁰⁶ See also History at <https://www.acet-uk.com/> and Dixon, 2004.

¹⁰⁷ See also History at <https://mildmay.org/>

¹⁰⁸ Detail relating to CAL is taken from personal memory, correspondence by email with Martin Pendergast and CAL Newsletters.

December 1988, the main presider being Bishop John Crowley at the French Church in Leicester Square (Pendergast, 1990, p.353). CAL organised training for clergy, pastoral workers, and concerned Christians throughout the next ten years, and developed a network of concerned and sympathetic clergy and laity around the country (Pendergast, 1990, pp. 353-354). Churches became increasingly aware of the necessity of addressing HIV and Aids during the nineties. Whenever CAL was approached to offer training in a given diocese, a parish or school, we insisted that at least one full day would be required to even begin to consider the many issues raised by HIV, and often the training would extend for two and sometimes three days. In these first two decades of Aids for any individual or family coming to terms with the diagnosis of a loved one, or needing to arrange a funeral, following Bill Kirkpatrick's guidance (1993, p.4) referred to above,¹⁰⁹ it was a pastoral imperative that sensitive support be available, from suitably trained and mature Christians, not only because HIV confronted individuals who wished to help with their own difficult and often unresolved issues around sexuality and death (Randall, 1994), but also because of the intense hostility and fear that was intrinsic to the experience for the person who was diagnosed. CARA conducted residential training weeks throughout the country, and the centre's volunteers undertook the course (Walsh, 2000, pp. 19-20). Both CAL and CARA sought to provide accurate information, and allow time and space for theological reflection upon the pastoral and theological issues raised for individuals and within communities of faith.

In London, the Salvation Army opened the Wandsworth Oasis AIDS Care Centre in 1989, a model which would be replicated in several places around the UK (Pendergast, 1990; Kirkpatrick, 1993, pp. 123-124).¹¹⁰ In 1990 parishioners of St. Botolph's Church in Aldgate organised the first ecumenical pilgrimage to Lourdes for those affected by HIV which continued annually. The ecumenical dimension and episcopal support is demonstrated by the fact that Catholic Bishop Victor Guazzeli (1920-2004) and Anglican Bishop Michael Fisher (1918-2003) jointly led the 1995 pilgrimage.¹¹¹ In 1992 Anglican Franciscan Brother Colin

¹⁰⁹ Quoted p.16.

¹¹⁰ See also Wandsworth Oasis History at <https://www.wandsworthoasis.org.uk/history-of-oasis> [Accessed March 2019] & CAL News no. 5 June 1990.

¹¹¹ CAL News no. 17 March 1995.

Wilfred (1937-2011) was the first person to be employed directly by the Church of England in a pastoral support role, based at St. Botolph's and covering East London.

In 1988 the Catholic Sisters of Mercy opened Bethany House in Cornwall, offering respite and care for people living with HIV and Aids,¹¹² and in 1991 Sr. Elaine Kelly, of the Helpers of the Holy Souls congregation started Centrepeace in the ground floor of a Convent in Camden, providing care and support for mostly African women and their families (Walsh, 2000, pp. 20-22).¹¹³ Elaine Kelly recalls how most of the women were afraid that their status might become known in their community. Kelly was preparing to attend the funeral of one of the women who had attended the centre before her death from Aids. Beforehand, another woman who also attended Centrepeace asked Elaine not to acknowledge her on the day of the funeral for fear that others would ask how they knew each other.¹¹⁴

Concerned clergy and other Christians got together to initiate local responses on an ecumenical basis, for example the Christians in Hackney AIDS Initiative (CHAI) was established following a 1988 'Christians Living with AIDS' Conference.¹¹⁵ By 1993 the London Ecumenical AIDS Trust (LEAT) had been formed to provide pastoral support. CARA arranged retreat weekends for those diagnosed, their families and carers. John White (1946-2019) a priest living with HIV facilitated a group for Catholics diagnosed with HIV or Aids at The Lighthouse.¹¹⁶ Also in 1990 Over 120 people attended the second 'Mass of Anointing' organised by CAL,¹¹⁷ and in 1992 CAL convened a specifically faith based support group run by and for people with Aids called 'Positively Catholic' which met monthly.¹¹⁸

These are just a few examples of Christian pastoral responses to HIV and Aids from the late eighties into the nineties. After a slow start the multiplicity of Christian pastoral responses can be seen in a comparison of Kirkpatrick's 'AIDS Sharing the Pain' first edition (1988) where, whilst making general reference to unspecified 'action on AIDS' taken by the RC and Anglican Church in England, the list of all available services (pp. 120-130) includes only one

¹¹² CAL News no. 4 March 1990.

¹¹³ Sr. Elaine Kelly is an example of someone who had previously been volunteering at CARA.

¹¹⁴ From conversation with Sr. Elaine Kelly on April 10th 2019.

¹¹⁵ CAL News no. 5 June 1990.

¹¹⁶ CAL News no. 4 March 1990.

¹¹⁷ CAL News no. 5 June 1990. The first Mass of Anointing was held at St. Aloysius Church Euston in April 1989, Chief celebrant Bishop Victor Guazzelli (Pendergast, 1990, p.353).

¹¹⁸ CAL News no. 10 Sept. 1992

specifically Christian HIV group, 'Christian Action on AIDS' (Pendergast, 1990, p.349). Whereas, in the new edition fifty Christian initiatives offering support around the country are listed (Kirkpatrick, 1993, pp. 125-130). The negative impact of 'unsympathetic and hostile' Christian responses was ameliorated for many, through personal pastoral encounters and Christian activism.

2.5 Theological responses: from dogmatic moralising towards compassion

Christian pastoral responses and actions (or inaction) in society, necessarily have a theological basis. As I have described above, the emergence of HIV in the West and globally, gave rise to theological responses, both from institutional figures and amongst ordinary people that focussed on issues of individual sexual morality, especially gay sexuality, and framed the pandemic as a symptom of moral decline in a sick society. Pamphlets and essays were written to counter the 'Aids as God's punishment' theology which, reinforced by the secular version of the same moralising in the press (Garfield, 1995, pp. 41-47) was the first and most vocal response.¹¹⁹ By the early nineties, some important theological works had been published (Cosstick, 1987; Kirkpatrick, 1988; Woodward, 1991). Perhaps because more considered theological reflection had occurred, and as the numbers of diagnoses increased and the personal stories and evident pain of people living with and affected by HIV had begun to be listened to in numerous personal encounters, there was a shift in theological emphasis.

Cardinal Hume's public responses provide an example of this shift from moralising about HIV and a concern to be clear about what is right and what is wrong, to the priority of compassion for those who suffer; and secondly, an increasing awareness that the pandemic challenged doctrinal certainties, in such a way that even to speak of sin was of no help in the face of human suffering. Mainstream Church leaders were, perhaps with Andrew's words above in mind, coming to understand that it is not possible to embody a compassionate Christ-like presence with those who suffer, whilst cradling a "moral sawn off shotgun...in your lap" (Holloway, 1994, p.154).¹²⁰

¹¹⁹ For example, a group called the 'AIDS Faith Alliance' produced a pamphlet for distribution through THT in 1986 entitled 'Is AIDS God's Wrath' to combat often expressed fundamentalist views (Pendergast, 1990, p.349; Kirkpatrick, 1988, p.121).

¹²⁰ Richard Holloway was Bishop of Edinburgh from 1986 to 2000.

Hume had framed the pandemic in 1986 as a ‘moral Chernobyl’¹²¹ and entitled a lengthy article in *The Times* in early 1987 ‘AIDS: Time for a Moral Renaissance’ (Berridge, 1996, pp. 107, 135). Immediately, Hume establishes promiscuous sexual behaviour “always...sinful...rapidly becoming suicidal” as the cause of Aids (Hume, 1987a, p.143). Likewise, in his preface to the first collection of theological essays to be published in the UK (Cosstick, 1987) his starting point is that “the Church must clearly condemn sin but never disown the sinner.” (Hume, 1987, p.1).¹²² In the same collection other religious leaders write in similar terms.¹²³ Space does not allow me to debate each of Hume’s points here, nor the focus on sin and individual responsibility made by some others in the same collection. Were I to do so I might begin by questioning whether the often used word ‘promiscuous’ has a clear meaning, and challenge the certainty of the implied and explicit judgements that populate several of these essays. What is evident in this collection is the tension between avoiding moralistic judgmentalism, whilst at the same time addressing questions about what is and what is not morally acceptable. For example, whilst Bernard Haring (1912-1998) strongly cautions against judging others, and warns that “a rigid and one-sided emphasis on sexual morality is counter-productive and causes dangerous reactions” (1987, p.90), he nevertheless states rather definitively that Aids is a “sign of a perverted sexual language, a sexual communication which lacks the truth of faithfulness and responsibility and which has, for many people become a kind of ‘sex consumption’ in which the sexual partner is a mere object.” (1987, p.88). I suggest that the reader living with HIV or directly affected, will feel that as a blast from Holloway’s metaphorical moral shotgun. Even so, ecclesial-self-critical theological questions are also raised in this volume of essays. Haring (p.92) suggests that Aids causes us to question how divorced and remarried people are treated within the Catholic Church, a question that controversially resurfaced some three decades later with

¹²¹ The Chernobyl nuclear reactor accident had occurred in April 1986.

¹²² Cardinal Hume also issued a letter to be read in all Catholic parishes in England Wales, at the Sunday Mass before World AIDS Day in 1988. In it he asks that people pray for all those affected, those who have died, for the scientific and medical communities and for carers. He recommends that all people, especially the young and those most ‘at risk’ be encouraged to adopt a “life style that will ensure...immunity from infection, and... development as mature and loving adults, in accordance with Catholic teaching.” CAL News, no. 1, Feb. 1989.

¹²³ The Anglican Archbishop John Habgood (1927-2019) rejects the description of Aids in “clear theological language as the judgement of God” but accepts that there is some connection between “what our society has been doing to itself and what has now come upon us.” He writes that moralising is unhelpful, not because it is in principle the wrong starting place, but because it is not an effective health promotion strategy and it contributes to the stigma attached to those who are ‘innocent’ (Habgood, 1987).

Pope Francis' encyclical 'Amoris Laetitia' (San Martin, 2017). Thinking about the emergence of HIV in Africa amongst the straight population, Haring also suggests that condom use may need to be tolerated as the lesser evil, especially in those marriages where the husband is HIV positive but the wife is not yet infected (p.92).¹²⁴ Jack Dominion (1929-2014) proposes that Aids and changing sexual mores in society calls for a more credible sexual morality, beginning with a consideration of "men and women as persons, and the link between them, based on love, rather than biological functions." (1987, p.72).¹²⁵ Cosstick and Radcliffe state bluntly that unless the Church is seen to be in solidarity with people with Aids "we might as well not say anything about morality at all." (1987, p.7).

Returning to Cardinal Hume, in his address to the CAL Conference of 1994 held at Vaughan House, Westminster (Hume, 1994), the shift in theological language and emphasis to which I am pointing is striking. Whereas in his 1987 preface he began with 'loving the sinner and clearly condemning the sin' followed by the Gospel story of the woman caught in adultery, here, with reference to Matt. 25:31-46 he states: "our starting point has to be the Gospel imperative to help those in need." He continues: "So the Christian response...should be to reach out and offer practical help" and he notes how "the judgement [in Matthews Gospel passage] is of the heart not the head. It is about how people have lived, about deeds rather than words." Even allowing for the audience of activists, pastoral volunteers and directly HIV affected Christians that Hume was addressing, there appears to me to be a significant change of theological tone. Not once does Hume mention sin, except by implication in regard to the judgement that will be made upon the Church for any failure to respond to those in need. The theological direction of learning from the phenomenon of Aids in society has been reversed. Far from needing to 'clearly condemn' anything Hume states: "In developing an informed and sensitive response to the needs of people with HIV or Aids the Church needs your experience, your commitment and your spirituality. Above all [the Church] needs the witness and gifts of those women, men and children who live with the daily impact of HIV or Aids." With these sentences, I understand Cardinal Hume to be acknowledging publicly a theologically important truth and a commonly reported experience, namely, that in ministering to people with HIV and Aids, many people

¹²⁴ Bernard Haring was an important Catholic moral theologian and Redemptorist priest.

¹²⁵ Jack Dominion was a British psychiatrist and Roman Catholic theologian.

discovered that actually it was they who were ministered to, rather than the other way around (Cosstick and Radcliffe, 1987, p.7; Cadwaller, 1992, p.xvi; Kirkpatrick, 1994; Smith and McDonagh, 2003, p.45-46). Or to put it another way, HIV ministry on behalf of the Church, is “not merely a matter of us bringing Christ to others but of meeting him in them. Christ always encounters us in people in need.” (Radcliffe, 1987, p.116).

Stephen Pattison (1990) makes a related point. The signs of what it means to ‘be church’ were evident within communities of people living directly with HIV. He describes his encounter with affected and infected people as a “spiritual experience...in the most worthwhile sense.” (p.10). He describes people living with Aids as bearing witness to “life, love, reconciliation and community alongside isolation, fear and destruction.” (p.12). However, that the Christian values of compassion, love, solidarity and justice were evidently alive within these communities, whilst liberating for some people, was deeply threatening to others. “The vision of a person fully alive, especially if regarded as immoral and sinful by virtue of sexual orientation or behaviour, walking around, accepting themselves and others, being angry and assertive” was “simply infuriating to the institutionalised Church.” (Pattison, 1990, p.15). Cardinal Hume’s 1994 words express the awareness amongst many Christians and some institutional leaders that those “living with HIV and Aids are a positive part of the body corporate [who] have much to teach the churches about life in the face of death.” (Pattison, 1990, p.17).¹²⁶ As I will show in my interviews with theologians later, for many Christians, the exposure to HIV and Aids during this time is recalled through similar moments of ‘graced encounter’.

What I am arguing here is that a shift in theological responses took place at least for some Church leaders and theologians from the start of Aids, when because of the twin forces of denial and disassociation silence prevailed; through a period of moral panic when HIV and Aids could not be ignored and theological voices tended to focus on matters of individual sexual morality and the protection of traditional Christian ‘family values’; to the mid-nineties when, because of the increasing numbers of people diagnosed locally and the

¹²⁶ It is probable that Cardinal Hume’s personal meetings with people with Aids influenced him. For example, Hume met CAL founder Peter Larkin, who I have written about in the previous chapter, and who is reported to have influenced Hume. Larkin was also a Director of the Aids self-help support group ‘Frontliners’. After meeting with Larkin Cardinal Hume made office space available at the Church of Our Lady of Notre Dame, Leicester Square, London, for the group (CAL News, no. 4, March 1990).

global proportions of Aids as a threat to every group in society, a deeper theological reflection had begun, indicating a growing awareness of the many and diverse ways in which HIV and Aids in society challenged the church. By the mid-nineties no mainstream Church leader in this country would entertain theological ambiguity in regard to the question of whether or not Aids was a type of divine punishment or consequence of disobeying church teaching (Pendergast, 1990 p.348).¹²⁷ People were beginning to appreciate that it was not so theologically simple after all. More importantly, I am arguing, that some Church leaders and theologians were beginning to sense that HIV in society ushered in what Enda McDonagh called *Kairos* time: a time of God's special presence and summons (McDonagh, 1994).¹²⁸

Up and down the country lay Christian volunteers and parish clergy were undergoing a similar journey. Under the leadership of CARA Education Worker Rob Willoughby, an ecumenical working group was convened in 1993 to meet the need for training and theological reflection within a parish setting. I was the CAL delegate to the group. For eighteen months we met regularly to devise an educational pack to enable local churches to address issues pastorally and theologically. Group-work sessions were trialled as part of CARA training weeks. In 1995 the seven-session course for use in faith groups was published (Willoughby, 1995). Drawing heavily on the personal written and recorded testimony of people living with HIV and Aids, including worksheets, session guides, and scriptural and theological resources, 'A Gift Wrapped in Thorns' was publicly launched at St. Anne's Church, Soho, on April 10th. The training pack was intended to facilitate theological reflection in an atmosphere of trust, within local faith communities, so that Christians could encounter HIV through the stories of people living with HIV, and make faith-sense of

¹²⁷ See also CAL News, no. 8, July 1991. I am describing a general trend within this country. Many Church leaders continued to frame HIV and Aids in simplistic ways. For example, at the Vatican Conference on HIV and Aids in 1999, Francisco Gil Hellin, Secretary of the Pontifical Council for the Family and later Archbishop of Burgos, Spain from 2002, in his presentation entitled 'The Place of Education in Values' asserts that "the values of the family...enable it to prevent children from being contaminated by AIDS" and ascribes HIV infection via sex or drug use to the "mental weakness" of individuals. He later indicts the families of those who use drugs calling them "weak or unstable" and his advice in regard to HIV prevention and the use of condoms is "chastity, self-control, education in real love, loyalty, and individual and social responsibility." (Gil Hellin, 1999).

¹²⁸ Enda McDonagh is a Catholic priest and Emeritus Professor of Moral Theology and Canon Law at the Pontifical University at Maynooth, Ireland. He was theological consultant on HIV and Aids for Caritas International.

personal experience with others. It was hoped, that upon completing the course the local community would devise an action plan to become a 'HIV friendly' church. Although dated now, this training course remains a model of best practice as a theologically informed resource. It represents a further theological and pastoral Christian response to God's special presence and summons.

2.6 Theological responses: from individual sin towards social justice

As I have described briefly above, during the first two decades, HIV posed serious pastoral and theological challenges for individuals, the church, and theologians. As Haring (1987, p.92) put it: "In the light of Aids, old burning issues of moral theology turn up with new ardour." In the sketch provided above I have described the ways in which some Christians sought to respond to the challenges of providing sensitive pastoral support to those affected. I have also indicated how challenging questions began to emerge for theologians. HIV and Aids has been an important influence upon the development of the Roman Catholic theological ethical tradition in the last forty years (Keenan, 2010, pp. 197, 216). A brief consideration of how the moral theological focus shifted from the locus of individual behaviour, towards an understanding of the pandemic as a matter of social justice in an era of globalisation, will conclude this historical contextualising of HIV. In the following section I will show how understanding HIV and Aids as a global pandemic has impacted locally, in terms of both pastoral and theological responses to HIV and Aids as a reality in our midst.

In the late eighties theologians were beginning to ask questions about and consider the implications of the trans-national dimensions of HIV. Again, for example Haring (1987, pp. 88, 92) cites 'sex tourism' as responsible for spreading HIV around the world, and along with the use of prostitutes in Africa by migrant workers, he justifies his conclusion that Aids is a sign of a consumerist approach to sexual relationships lacking truth and responsibility. As already noted above, Haring also considers that condom use within marriage may need to be tolerated. Paul Nunn (1987, p.31) speculates that in view of the predicted scale of infections in Africa, the "Churches should overcome their scrupulous reluctance to become involved in Aids."

By the mid to late nineties the global scale of Aids as an international emergency was more evident, and a theological reframing of HIV, away from individual morality, towards understanding the pandemic as a matter of social justice, began. I am not suggesting that

questions of individual sexual morality, nor the tensions between effective and ethical responses to the pandemic as a public health crisis and the Church's duty to respond compassionately have gone away (Clague, 2014; Grotenhuis, 2014). As indicated already, the various debates persist in all churches. What I am arguing is that this shift in theological attention had unintended pastoral consequences here in the UK. A consideration of three theological contributions will suffice to make my point.

McDonagh's 'Theology in a Time of Aids' (1994) remains influential,¹²⁹ in which he states that the "questions raised for theology may not be confined within the conventional limits of moral theology" and "go well beyond the tabloid writers' concerns with condoms and needles" (McDonagh, 2007, p.43). He argues that the truth, freedom, justice and peace, proclaimed by Jesus in his public life – 'Kingdom values' - not only define Jesus' earthly mission and ministry but the mission of the Church today. The Church is called to participate in the development of "God's new creative activity" (p.48), building a new kingdom that prioritises those who are poor, sick and socially excluded through active caring, loving personal relationships and structural reform. After the manner of Jesus, these are the primary Gospel values which should inform the Church's response to HIV and Aids, because they manifest the presence and power of God in the midst of the pandemic, through personal interaction and within social structures (p.49). This moral framework theologically broadens the terrain of inquiry. McDonagh responds to the challenges of a global pandemic by asking not just what is right and what is wrong, but what is just, and what is most important theologically. He offers Kingdom values as the moral principles that come first in the ordering of theological, pastoral and political Christian responses.¹³⁰

With Ann Smith in 2003, these Kingdom values combine with Catholic Social Teaching and are applied practically to the ethical dilemmas and challenges faced by those living with and working to alleviate the suffering of HIV and Aids within the context of international

¹²⁹ By this time McDonagh had been engaged by Caritas Internationalis as a theologian, visiting Africa and elsewhere, to develop some theological principles that might inform the response of Caritas to the pandemic. The article originally appeared in 1994 and an adapted version is reproduced in Gill, 2007. Vincent LeClerq (2010) uses McDonagh's Kingdom values as the framework through which he explores the experience of living with and responding to HIV and Aids to elaborate a practical "ethics of Aids" (p.53).

¹³⁰ McDonagh (2007, pp. 49, 51) writes that other moral values, for example chastity, whilst important, are secondary in the context of an authentic Christian response to a global pandemic. The interaction between the primary Kingdom values and their influence upon shaping secondary values must be kept continually in mind.

development. The pandemic as an issue of social and economic justice is clearly presented. The complexities of addressing the suffering that both causes and is caused by HIV in poor communities is given a visual representation in 'The Problem Tree' (Smith and McDonagh, 2003, p.56) which exposes the deep roots of poverty, inequality and political instability rendering whole communities vulnerable to HIV. Above these are sexual violence, ignorance, and migration amongst other conditions, which make individuals in these communities more vulnerable to HIV. The branches of the tree fan out to show how HIV and Aids impact upon societies and individuals exacerbating poverty, gender inequality, increasing numbers of orphans, draining scarce health and other resources, bringing death and mourning, negative economic impacts and so on. To intervene effectively means taking account of and addressing the social, political and economic causes and consequences of HIV and Aids.

Kevin Kelly's (1998) 'New directions in Sexual Ethics: Moral Theology and the Challenge of AIDS', reflects upon the pandemic globally. I will say something about this book in chapter four where I recount my interview with him. It suffices here to note this influential work, because it illustrates an approach to moral theology which does not avoid issues of individual morality, for example the questions of condom use, Christian teaching on marriage, and gay sexuality which Kelly treats thoroughly, but he firmly contextualises these issues within the structural sins of global inequality, poverty, gender inequality and Patriarchy (1998, pp. 20-21). Kelly's work is grounded in the experiences of individuals living with HIV and Aids. The very challenging conclusions that he comes to in the book came via encounters with those he met in Uganda and elsewhere, again as types of graced encounter with the Christ or Christa living with Aids (pp. 13-21). However, the theological significance of this 'time of Aids' he says, is the "clear and compelling call from God to...conversion and action" meant for the whole human family (p.207). "It belongs to the prophetic role of the Church to play a part in enabling that to happen" (p.208).

These theological contributions indicate how, over the course of two decades the theological locus of inquiry has been totally re-oriented, from the individual-personal to the social-global. A similar shift away from personal sin to structural sin is observable ecumenically (Kurian, 2016, p.12). The theological demands of social justice take priority. Challenging what Keenan and McDonagh have termed 'structural violence' (Keenan and

McDonagh, 2009), confronting the structures of sin that create poverty, forced migration, gender inequality, ignorance, discrimination and prejudice - the issues that contextualise and increase the vulnerability of those most affected – these are the prior ethical and theological considerations before the Church can talk meaningfully about the sins of individuals living with and affected by HIV (Cahill, 2000; Iozzio, 2008; Kennan and McDonagh, 2009). The roots of structural sin are located more in the West than in poorer countries ravaged by Aids (Kelly, 1998, p.21). It follows that the moral responsibility for addressing these wrongs and doing what is right rests with those who have power, influence and resources including the Institutional Church. By the beginning of this century, and I suggest in a way that continues today, the Western theological gaze is directed towards HIV in global perspective, and with few exceptions, HIV and Aids is addressed within the context of international development (WCC, 2000; Messer, 2004; Cimperman, 2005; Overberg, 2006; Gill, 2007; Keenan, 2007a; Iozzio, 2008; Leclercq, 2010; Trentaz, 2012).¹³¹

2.7 HIV ‘over there’: Christian responses in England and Wales today

That the attention of theologians and the resources of the Church have been directed to the situation of those who are the poorest in the world, where the epidemiology of HIV infection is greatest is right and just. However, as Christian responses scaled up from the early nineties internationally, concern for the situation of people living with HIV and Aids in this country and I suggest in all richer ‘developed’ countries, has diminished.

Let me begin with a statement of fact. Recall the flourishing of Christian pastoral responses from 1988-1993 that I have written about. With the exception of The Mildmay which now specialises in the treatment of people with HIV and cognitive impairment, none of the pastoral ministries mentioned above are in existence. The most recently closed were LEAT in 2014 and CARA in 2018. Wandsworth OASIS remains a registered charity, but now manages several charity shops generating grants for HIV related charitable causes. Undoubtedly, funding issues and the reorganisation of HIV services commissioning by local government

¹³¹ There is also a canon of theology produced from a specifically African perspective. E.g. Dube & Kanyoro, 2004; Orobator, 2005, 2009; Phiri & Madar, 2006; Dube, 2008; van Klinken, 2011; Mombé et al. 2012; Byamugisha et al. 2012. African authored theological responses have arisen mostly post the year 2000.

referred to above, was a factor in the closure of many of these agencies as it was for many voluntary sector HIV charities.

However, there are additional reasons for the current lack of pastoral support and Christian ministry with and for people living with HIV in this country that I want to highlight. A consideration of the development of ACET and the closure of CAL will provide examples.

ACET also continues, but no longer provides pastoral support directly for people with HIV in this country. Their main activity in the UK today is the provision of Christian sexual health and relationships education in schools. As a medical practitioner ACET founder Patrick Dixon was aware of the acute need for both education and care in Africa (Dixon, 2004). ACET developed international ministries from 1990 onwards, and coinciding with more effective ARV treatment the London based home care program ceased in the mid-nineties. Today ACET has a network of ministries providing care and support and training in Africa, Asia and Eastern Europe. In many ways the development of ACET typifies what I am getting at. With adequate medical provision in Britain, ACET has directed attention and resources internationally to those countries where medical treatment is less available and the population of affected people is greater. In terms of the pandemic as a call to mission, I suggest that many Christians then and now feel much more comfortable with this understanding of Aids as something far away rather than something in our midst. Understanding HIV as a medical condition requiring a medical response especially within the context of missionary activity in the 'third world' is something that historically Christians have understood and arguably, done quite well. In terms of HIV prevention and education, the opportunities for evangelisation, including the promotion of orthodox Christian teaching on sexual morality and 'family values' were vast, and less likely to encounter serious challenge or opposition, as these approaches did within the West.

The closure of CAL by a majority vote at the AGM in 1999 makes a second interesting case study. At the time I had resigned from the Board to take a job with the Iona Community in Scotland. My knowledge of the detail of what happened is from the reports I have heard from others and is rather incomplete.¹³² I do recall discussions with other Board members in

¹³² Notes from the 1999 Annual General Meeting which voted to close CAL are not available. Although the exact reasons for the vote are not available as a written record, I have spoken with others who attended the AGM including founding members Martin Pendergast and (now Rev.) Peter Harris. Martin was opposed to

1998 about CAL's purpose and mission. The 'argument' as I remember it, went something like this: now that medication for those infected here is proving effective, and deaths from Aids are in decline, CAL should focus more upon the pandemic as a global health crisis. The national HIV prevention strategy had minimised rates of new infections in comparison with other European countries. The greatest and most urgent need was to respond to the immense crisis in Africa. I was one of those who argued strongly that the Church's response to HIV as an international development issue belonged with Cafod, the nominated lead agency for HIV and Aids within Caritas Internationalis. Secondly, the smaller numbers of people infected and affected in England and Wales in comparison to the millions infected and dying in developing nations did not justify 'abandoning' people living with HIV in our midst. The practical, pastoral and spiritual needs of affected people in this country had not gone away simply because better health care was available.

At the same time, I recall discussions about the particular vulnerability of women to HIV and Aids. In Africa and in the UK women faced difficulties that men and in particular gay men did not. It is accepted, that approaches to HIV and Aids within the context of international development must prioritise the needs of women. Locally, the work of Sr. Elaine Kelly mostly with African women left the CAL Board in no doubt that women encounter additional challenges because of their inferior status to men in both marriage and society; their vulnerability to sexual violence; and their responsibilities for children (Smith and McDonagh, 2003, pp. 101-103; Sowle Cahill, 2008). That women required sensitive specialist pastoral support and 'safe spaces' in which to meet was not in doubt. The argument was made within CAL by some members that as gay men in the UK had access to a range of secular HIV support services and developed networks of social support, CAL's resources could be better used in supporting women and their children, both locally and internationally. My position whilst still a member of the CAL Board reflected my previous assertion, the needs of any person living with HIV in this country should remain our priority. CAL needed to support and advocate for the needs of women, straight men, gay men, and their children. I remember feeling defensive at the time, because the issues were presented,

closure whereas Peter appears to have argued in favour of the motion, although he has not been clear with me as to the reasons why he took this position. The account I give here therefore is my account from memory of the circumstances that preceded the AGM in 1999, and from reports in CAL News.

it seemed to me, as a choice between the needs of women and children in opposition to the needs of gay men. As gay men remained the group most affected in British society, it was unthinkable to me that we should not continue to advocate for them and support them. Gay men and women living with HIV, IV drug users, and Africans and other migrants were each subject to marginalisation and disadvantage in distinct ways. CAL's mission was to be in solidarity with each of these communities. It was not for us to choose between them, as though choosing between the more or less deserving, or the 'innocent' and the 'guilty', but to assist any person and serve each of these vulnerable communities as best we could.

In my opinion controversy over the Institutional Church's relationship with gay people, and the organisations that represented them was an added factor that led to the decision to close CAL. Ongoing public disputes within the Anglican and Roman Catholic Churches had created controversy that challenged the CAL Board to take a public stance. For example, on the occasion of the twenty-fifth anniversary of the founding of the Lesbian and Gay Christian Movement (LGCM) a service was held in the Anglican Southwark Cathedral. Some Christians protested, finding the liturgical 'celebration' of LGCM infuriating. Appearing to give episcopal and institutional endorsement to the LGCM crossed a line. The organisers of the protest encouraged others to express their disapproval by withholding parish contributions to diocesan finances. Surely with a view to their own defence against any negative public criticism or media headlines, the organisers had publicly urged supporters to donate money to Christian HIV and Aids charities instead. Once more, in view of the affliction of HIV and Aids impacting the gay community, the tension between appearing hostile and uncaring and therefore un-Christian, or to put it colloquially, 'not loving the sinner', and the desire to assert what is right and what is wrong and be clear about the traditional Christian disapprobation of gay sexuality is evident.

A joint statement in support of the LGCM from the Chairs of CAL, CARA and the Rain Trust was published in CAL News stating that: "The acceptance of any monies which arise from attempts to deny gay and lesbian people their right to meet and be met by Christ in prayer and worship, would contradict our core values. Furthermore, it would be an insult to the memory and lives of those with whom we journey, day in, day out."¹³³

¹³³ CAL News, no. 23, Dec. 1996.

There had also been controversy when the Catholic lesbian and gay support group Quest, refused to affirm Catholic teaching in regard to gay sexuality. This brought them into public conflict with Cardinal Hume who directed their exclusion from the official Roman Catholic Directory for England and Wales in 1999 (Baklinski, 2017).¹³⁴ My recollection is that within the midst of this public spat, CAL attended the annual Gay Pride celebrations and occupied a stall next to the Quest stall, close to the LGCM stall in an area designated 'Christians at Pride'. It was normal practice for CAL to be present at this important annual event both as Christian witness and as a form of outreach, and the allocation and location of stalls was a matter for the organisers of Gay Pride rather than the various Christian groups present.¹³⁵ However, CAL faced criticism from some detractors as having demonstrated dissent from Church teaching by the apparent collaboration with Quest in this way. Some years earlier, correspondence in the Catholic press had asserted that CAL could not take a non-judgmental approach to HIV and at the same time claim to be a Catholic organisation; unjustified 'suspicion' that CAL was not 'properly Catholic' was not new.¹³⁶ A small but well organised group of people had sought for several years to undermine CAL by way of gossip, personal smears, letters to the bishops and even attending CAL events to gather evidence of 'unorthodox' preaching or teaching.¹³⁷ Whilst theologies of 'the wrath of God' were replaced with more sensitive responses both pastorally and in terms of Church leaders statements, for some members of the church the visible presence of gay men and those in Christian agencies who remained in unapologetic solidarity with them, was always 'simply infuriating' and remained threatening.

I cannot argue conclusively that CAL closed in 1999 because of these tensions in the Church. There is no evidence that CAL closed because of direct pressure from the episcopacy, and certainly not from Cardinal Hume who was consistently supportive. However, it is a factor that I believe must have influenced the decision to close CAL.

To be pastorally involved with people affected and infected with HIV in the nineties was emotionally, psychologically and spiritually demanding. As Cardinal Hume acknowledged the

¹³⁴ See also Cardinal Basil Hume, Obituary, *The Telegraph*, 18 Jun 1999.

¹³⁵ CAL News, no. 8, July 1991.

¹³⁶ CAL News, no. 8, July 1991.

¹³⁷ CAL News, no. 18, June 1995.

tasks of “education, prevention, treatment and care [were] not easy, and at times [people felt] isolated, under attack or misunderstood” (Hume, 1994). The increasing focus on Aids as a global crisis alongside a diminished sense of emergency domestically, perhaps in combination with a sense of exhaustion for many, provided the conditions within which, whether consciously or not, the difficult and challenging theological and moral issues around sex and gay sexuality in particular with which the Church and individual Christians were confronted could be avoided. And being avoided the potential for conflict between Christians, and especially within a Roman Catholic context where unity is highly valued and measures to enforce ecclesial discipline are often taken, any tensions between and within the clergy, the laity and the hierarchy might quietly subside.

I began this section by stating that none of the Christian pastoral responses that arose in the late eighties have continued. It is my argument that the Church’s hasty withdrawal from the site of suffering of people living with HIV in our midst began as soon as treatment became more effective. I sometimes describe it as being like a collective breath being taken followed by a deep sigh of relief that as Church we would no longer have to deal with messy and theologically difficult issues at close quarters. The focus on Aids as something that happened somewhere else takes us right back to those first years of inaction. Perceiving HIV infection as primarily a medical condition allowed Christian agencies to withdraw from the local site of suffering. Denial and the sense of distance from HIV once again enabled avoidance of the fears and discomfort of forced encounters with sex, sexuality and mortality.

2.8 Summary and conclusion

In this chapter I have contextualised the present study historically through a consideration of pastoral and theological responses to HIV and Aids. Broadly, Berridge’s (1996) time-frame of a period of relative inactivity marked by denial, followed by a type of war-time response in the mid-eighties, toward more organised and ‘stable’ responses during the nineties, can be applied to the Church as well as to the government and society generally. As a public health emergency the major change that brings us to the present day has been more effective treatment and a decrease in the numbers of people dying from Aids in this country. As a crisis of faith the major shifts have been from simplistic moralising to more considered theological and pastoral responses as the church began to encounter HIV and

Aids locally. However the appreciation of Aids as a global pandemic, along with a narrow understanding of living with HIV as a manageable medical condition, has allowed the churches collectively, to withdraw from direct pastoral provision for those infected and affected within our society. As I have already stated previously, in 2003 CAPS began in order to continue the work of CAL.¹³⁸ It is now the sole remaining Christian pastoral ministry in this country of any sort.¹³⁹ In terms of theology, a similar shift away from the local and individual to the global and social aspect of Aids has occurred.

In this chapter and chapter one I have argued that there are two historical constants that are evident. The first is HIV related stigma which has persisted throughout the story of HIV and Aids, in communities and in the churches. The second are the theological debates and ecclesial tensions that HIV has exposed within the churches. HIV and Aids continue to expose the 'battle lines' over sexual purity and what the Church teaches is right and wrong, and some Christian's need to defend the boundaries of Christian faith and community against the threat of moral danger that HIV still represents.

How then might the reality of HIV within the body of Christ, in the Church in England Wales, be thought of or understood today? Given all the preceding evidence, I argue that HIV is not thought about within our churches because it is not considered to be something that affects us. What it means cannot be understood because those Christians (and others) living with HIV are no longer encountered within the churches. When it is mentioned HIV is spoken about as being in the past. Thus ignored, the wider Church cannot care for or respond to the needs of people living with HIV in our midst because they are invisible. These sisters and brothers living with HIV have been relegated to the private place of the HIV clinic and

¹³⁸ Martin Pendergast, a founding member of CAL, was also a founding member of CAPS. The Trustees of CAPS, included people previously active in HIV and Aids ministry. The trust deed names them as Robert Loftus; Anne Gayer & Roy Parr, with Rev. Bernard Lynch recently returned from the USA where he had been controversially involved in HIV ministry (see Lynch, 1993; 2012) and Stephen Portlock, SJ, who would become the co-facilitator with myself of the Positive Catholics peer support ministry.

¹³⁹ There remain a small number of HIV charities registered with the Charity Commission as currently operative, which have had an historical connection with the Church i.e. The Rain Trust in London and Faith in People in Leicester but these charities only operate locally rather than nationally, and following the pattern of services provision by CARA in it's last decade of operation, none of these agencies provide services that are identifiably religious or faith based in any way. Although support for people living with HIV can always be considered Christian in the sense that these are 'works of mercy', neither CARA, the Rain Trust or Faith in People provide identifiably Christian ministry (e.g. spaces and time for prayer) and do not claim in any public way that their services are delivered in the name of the Church.

doctor's surgery where their medical condition can be assessed and managed. Yet, as I have shown above, the population of people living with HIV in this country are amongst the most disadvantaged in contemporary society. Whether because of social isolation and marginal status; the fact of belonging to a despised social group; or physical and mental illness, many of our sisters and brothers living with HIV qualify as being amongst those who are poor and in need to whom Jesus refers in Matthew's gospel (Matt. 25:31-46). As I have also described above, a majority of those receiving medical treatment for HIV today say that religion and spirituality is important to them, but only a minority have spoken about their status to anyone in the church, and of those who have, almost half indicated that they did not feel supported or understood by other Christians. If as Church we profess a preferential option for the poor then how are we to express this if we never see, hear from, or encounter people living with HIV today?

As importantly, I have described in this chapter, how historically the embodied encounter with HIV has often been an encounter with Christ, a graced moment of conversion, for the Christian. When gay men and later marginalised women, organised communities of support and care within which all the signs of Christian life were evident, many who witnessed it, knew that there was something 'spirit-filled' about those groups from which the whole Church might learn (Henderson, 1990). If, as I am arguing, people living with HIV have something of value to share with the wider faith community, how can this happen without relationships or encounter?

In this chapter I hope to have reminded the reader of the ways in which the phenomenon of HIV and Aids in Church and society was encountered and responded to historically. This then provides the background and context for the encounters with those who will tell their stories of living with HIV in the pages that follow.

Chapter 3. Approaches to Research

3.1 Introduction

In previous chapters I have described the background to and reasons for this research. I have described how my own closeness to the subject matter has motivated me, and argued that the situation for Christians living with HIV in the UK today is misunderstood and largely ignored within the church because people living with HIV remain hidden. In this chapter I will discuss my approach to the tasks of research. I will begin with a discussion of the approach I take and continue to explain the theoretical justification for the methods I have used to conduct this study. I will describe how I have adapted qualitative research methods to pursue this inquiry. This chapter makes the theoretical underpinnings of my methodology explicit, and will show a rigorous and credible approach to the methods used. However, I have not applied any one method rigidly or comprehensively. Rather I have drawn from and applied them insofar as I have found them useful in pursuit of theological meaning (Swinton and Mowat, 2006, pp. vii-viii). Previously I have explained how this study relates to practical and pastoral theology. I will close this chapter with a consideration of how faith and methodology have been combined within this research.

In what follows I will be discussing in theoretical terms, for the most part, how I undertook this research: I will talk *about* the search for theological meaning; and *about* the people who are the main participants in this research. In chapter four the theological landscape touched upon in the previous chapter within which this study is situated will be returned to in my interviews with theologians. In chapter five the encounter with the people about whom I am writing will begin in earnest. However, at this point it is important that I make transparent the epistemological rationale and the manner and ways in which I have pursued this research.

3.2 From the incredible to the credible: influence and change

For this study to have actual relevance, it must be considered credible in two important ways: first the account of lived experience that I offer must be convincing; second, any conclusions, insights or meaning(s) that I propose must be considered reasonable to others, based upon the description of experience which I present. If the experience of living with HIV, as described, does not 'ring true', then it is most likely that any subsequent

interpretation will lack authority, and as importantly to me, fail in the task of influencing some degree of change in others.

Let me try to explain, with an example of something that happened to me at the very early stages of my formal research. I was at Nottingham University, giving a talk to other research students and theologians. One of many presentations that day, my talk explored the relevance of the spirituality of Julian of Norwich as a helpful guide in any pastoral response to those diagnosed HIV positive.¹⁴⁰ Using quotes that I had collected from Christians who had attended a Positive Catholics retreat, I argued that people in our churches living with HIV, are often unseen, unnoticed, and silent, because of the stigma associated with HIV. This stigma, which persists in the church and wider society, means that many people with HIV do not feel 'safe' or fully welcome in the church. So, the person living with HIV will often suffer in silence. A person cannot feel 'at home' in a community where they must keep very significant facts about themselves, secret. Even when overt signs of hostility or rejection are not present, most of us can relate to the phrase 'I just didn't feel that I could be myself'. It is surely a very human feeling, and most of us can easily recall situations in which we have felt uneasy, anxious, or apprehensive. In short, I suggested that generally, people with HIV do not feel welcome in our churches, with the implication that something about church life and culture needs to change. After my talk, there was a chance for a few comments and questions.

A man challenged me, in what I took to be a slightly 'offended' tone: "I do not recognize this church that you describe where people feel unwelcome" he said, "everyone is welcome in our church". I asked him to describe how people infected with HIV would *know* that they are welcome in his church. Was there a statement of welcome, or any sign such as leaflets or posters in the church that addressed the issue of HIV, and thus might indicate a degree of awareness or sensitivity? "All are welcome" he insisted, "do we have to put up a sign for every different group? One saying women who have had abortions are welcome, or divorced people are welcome? That's the point of church! Everyone knows that anyone is

¹⁴⁰ The presentation was later formulated as an article and published in *The Pastoral Review*. See Manning, 2011.

welcome.” The man seemed to be disputing not only my argument, but denying the experiences of those whose words I had used.

Of course, I agree with him that one of the ‘points’ of church is that everyone is, or should be welcome. After all, Jesus extended His invitation to all people.¹⁴¹ At this stage I will not enter into the discussion about what actually constitutes welcome in the church. For the moment, what matters is that this man was not convinced by my argument. I was taken by surprise. I had assumed that whatever else might be challenged, the lived experience of others which I was reporting upon would not be open to doubt. Yet I had failed to persuade him that the experience I described was common, or alternatively that the anxieties I reported were reasonable. My evidence was not good enough. I had failed to communicate effectively and in all probability, the man will not have gained any new insight into the situation of people living with HIV. He seems to have implied that there was no need for change in his church. So, I failed to influence what I would view as desirable change. No action needed, in part, because I did not make a convincing enough argument for change.

I am interested in influencing change for the better, because I care passionately about these issues. Therefore, learning from my experience in Nottingham, I intend to present here, sufficiently reliable evidence, that supports the arguments and assertions I make, and to do so in a way that is also credible.

The ways in which I have approached the tasks of researching and presenting this study, will add or detract from the overall credibility of my thesis. It is important therefore, to be explicit about the ways in which I have approached the task of research, and why I have chosen the methods that I have. I have been guided by Wolcott who advises that “Theory ought to be *useful*, not simply for show” (Wolcott, 2009, p.71; Greener, 2011, p.1), and by the advice of Smith, Flowers and Larkin who similarly warn of the “danger of ‘methodolatory’ (the glorification of method)” (Smith et al. 2010, p.5). Therefore, I use accessible language wherever possible, whilst explaining the theoretical underpinnings of the approach I have taken, sufficient for the purposes of this research. In this chapter I will

¹⁴¹ Mt. 11:28

show that the evidence I present can be relied upon, because of the methods used, and the approach I have taken.¹⁴²

3.3 Methodological approach: why qualitative research?

In order to explore the meaning of living with HIV I have chosen a qualitative approach. This means that I have used interview techniques, close observation (van Manen, 1994, pp. 68-69; Clandinin and Connelly, 2000, pp. 80-83) and the examination of texts, to access the source material that can be considered the evidence for this study. Listening to the stories of others, participating as an 'insider' in the ministry of Positive Catholics, and analyzing the written material available, is how I come to know, what I think I know. Throughout this thesis I will refer to this evidence as the basis for my argument.

Thankfully, it is no longer necessary to defend the use of qualitative research, as it once was (Wolcott, 2009, p.26). Denzin and Lincoln (2003c, p.1) describe the history of qualitative research as "long, distinguished, and sometimes anguished". Certainly within academia there has been much debate about the validity of qualitative research as an empirically grounded exercise (Denzin and Lincoln, 2003c, pp. 13-17).¹⁴³ Today however, there are a range of methods used which seek to capture something of a given experience or situation, and within the social sciences, both academically and 'in the field' qualitative research is employed to gain understanding and fresh insight.¹⁴⁴ When inquiring into the *meaning* of an experience, such as living with HIV, qualitative research is both justified and most likely to

¹⁴² Harry F. Wolcott was Professor in Anthropology at the University of Oregon. Jonathan A. Smith is Professor in Psychology, Birkbeck, University of London. A leading proponent of Qualitative Research in psychology, Smith has devised Interpretative Phenomenological Analysis (IPA); a methodology derived from hermeneutic phenomenology which is the methodological approach adopted in this research. Prof. Paul Flowers is based at the Institute for Applied Health Research, Glasgow University. Michael Larkin is Reader in Psychology, Aston University. Together Smith, Flowers and Larkin have published the first textbook on IPA (2010 – first published 2009). They have also applied IPA to people living with HIV, and share research interests in Public Health, sexuality, and sexual health.

¹⁴³ Norman K. Denzin is Emeritus Professor of Communications, Sociology and Humanities at the University of Illinois. Yvonna S. Lincoln is Professor of Higher Education, Florida Atlantic University.

¹⁴⁴ For example, in the UK most spending on HIV health promotion initiatives will require some mix of both qualitative and quantitative data if funding is to be justified, and the effectiveness of a given intervention demonstrated. Quantitative analysis will help us know such things as the age and numbers of people involved; their ethnicity; and where they live. Decisions to allocate more resources within groups and geographical areas that evidence the higher rates of HIV infection will be heavily reliant on quantitative data. Obviously, this sort of data collection allows for planning appropriately, and justifies the allocation of resources. Statistical data alone however, can only give part of the picture. Knowing how many people attend a peer support group for example, does not tell us anything about why they attend, or how it helps them in their daily life. To understand these aspects, requires an approach that asks people in some way to describe their experience.

achieve meaningful results (Todres, 2011, p.65).¹⁴⁵ As Laverty (2003, p.2) puts it, this study is more concerned with “discovery, description and meaning rather than prediction, control and measurement.”¹⁴⁶

Denzin and Lincoln offer a helpful generic definition: “Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomenon in terms of the meanings people bring to them.” (Denzin and Lincoln, 2003a. pp. 4-5).

As an umbrella term, qualitative research allows for a wide variety of methodological approaches. Creswell describes five of the most well established¹⁴⁷ and names several shared characteristics which I will summarise as follows:

- Researchers collect data ‘in the field’ amongst the people who experience the issue or problem under study. Face to face interaction with these people allows for conversation and observation in their natural setting. The researcher values proximity and seeks to become familiar with the lived experience of others through close contact.
- The researcher is key to the process of collecting data and recognizes that their involvement and interaction is personal. That is to say, what the researcher brings to the situation, their own background, history, personal context and prior understandings, will have an impact on the way in which the researcher sees, hears, and understands the situation under study.

¹⁴⁵ Les Todres is a clinical psychologist and Emeritus Professor of Qualitative Research at Bournemouth University.

¹⁴⁶ Susann M. Laverty PhD, Clinical Psychologist at the University of Alberta, Canada.

¹⁴⁷ John W. Creswell is Emeritus Professor of Educational Psychology at the University of Nebraska-Lincoln. The five approaches Creswell explores are Narrative Research; Phenomenology; Grounded Theory; Ethnography and Case Study. (2007, pp.36-39).

- As I have emphasized already, the focus throughout the research process is upon accessing the meaning that participants hold about the problem or issue. This means that the researcher will seek to avoid imposing their own predetermined meaning, directly or indirectly.
- The research process is flexible, with the researcher usually using multiple sources of data from which identifiable themes can emerge. As the main aim of qualitative research is to learn about the issue from those who participate, the methods of inquiry, the questions asked, the people involved, even the site of inquiry, may change as research proceeds. The actual involvement of participants may affect each of these aspects of the research, due to their personal circumstances, as well as the views they express. The study may be continually modified in order to access the meaning(s).
- Qualitative research aims to give a complex picture of the problem or issue under study. The various factors at work in a given situation, and how they interact with each other is what the researcher seeks to describe. (Cresswell, 2007, pp. 36-39).

This research then, is qualitative, because this methodology is most appropriate to an inquiry into the lived experience of people. By attending to the meanings people ascribe to experiences which they, and I, seek to make some sense of, I hope this study will yield fruits of fresh insight and show a depth of understanding.

3.4 Epistemologies, Methodologies, and Methods in Qualitative Research

In the literature on qualitative research, issues of method, methodology and epistemology are sometimes defined in confusing ways. Lavery (2003, p.24) makes this point when she says “researchers need to ensure the credibility of the study. Issues of rigor in interpretive inquiry are confusing to discuss, at times, as there is not an agreed upon language used to describe it or one universal set of criteria used to assess its presence.” Carter and Little (2007)¹⁴⁸ provide a model for understanding the relationship between and application of, these three fundamental facets of research. Reading their article came as an ‘aha moment’,

¹⁴⁸ Assoc. Professor Stacy Carter is Deputy Director of Sydney Health Ethics, Faculty of Medicine and Health, Sydney University. John Miles Little is Emeritus Professor of Bioethics and Medicine at Sydney Health Ethics.

when I thought I had finally grasped sufficient theory to justify my research approach, or “strategies of inquiry” (Denzin and Lincoln, 2003b).

As the theory of knowledge, epistemology is concerned with the limits of what can be known. As a philosophical discipline, epistemology critically interrogates the sources and ways in which one arrives at that which is claimed as knowledge. It considers questions of what can be reasonably believed and what can reasonably be claimed to be true (Audi, 1998, pp. 1-10 Cottingham, 2008, p.2; Bunnin and Yu, 2009, pp. 218-219). In this chapter I will make explicit the sources or grounds for (Audi, p.7) the claims to knowledge that I present in this study. I consider it sufficient for the arguments that I make, especially those that will follow in Part II, to use Carter and Little’s (p.1317) working definition that “epistemology can be thought of as justification of knowledge”. In this study therefore, my consideration of epistemology has the practical function of asking the question ‘how do I know what I think I know’; justifying my methodological approach; and making apparent for the reader how I have arrived at the arguments I make. Knowledge requires justification, if it is to be deemed credible. Methodology, they explain, “...provides justification for the methods of a research project” and is distinct from the methods themselves, which are the tools or techniques that the researcher uses to gather the relevant evidence (Carter and Little, p.1317). Their diagram helps to clarify the interactive relationships between epistemology, methodology, method, data and analysis, and the emergent knowledge.

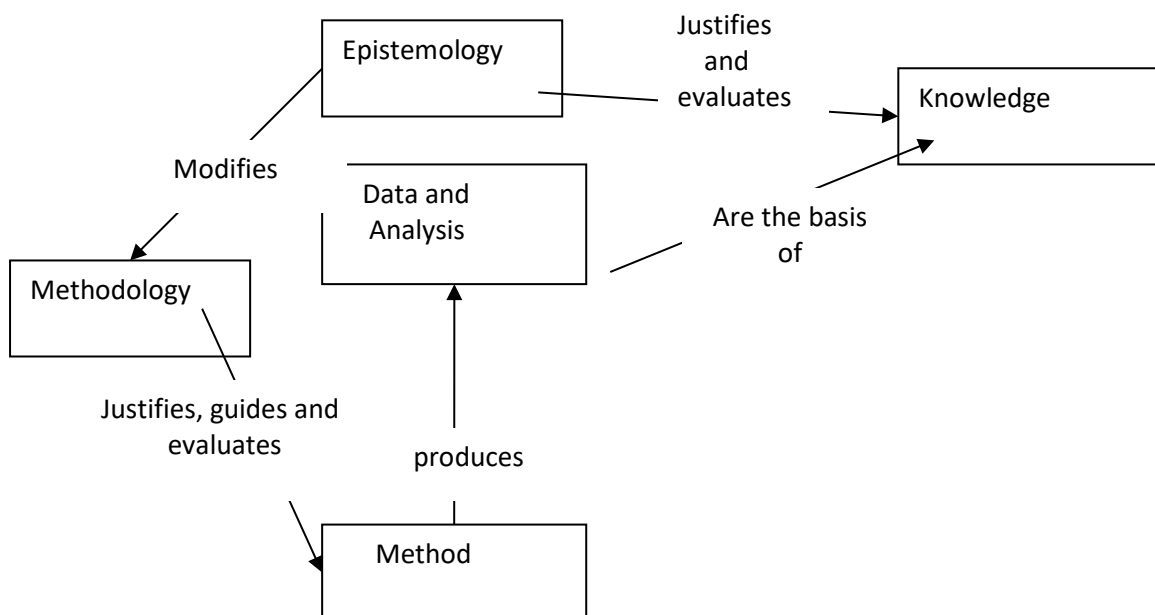


Figure 1 Carter & Little, 2007, p.1317

3.5 Epistemology

I begin with an assumption that it is possible to find out about the reality of life with HIV through being alongside, and engaging in dialogue with others living with HIV, and through this relational process a deeper understanding will emerge, and new knowledge about others and their situation will be revealed. These assumptions are part of a set of beliefs about how we can understand human experience. Also called a 'worldview' in the research literature (Cresswell, 2007, p.19), the basic set of beliefs that I hold guides the way in which I conduct my research. Clearly, if I believed that only the 'positivist' approach to inquiry was valid, then I would see 'objectivity' and 'distance' as important. However, my worldview assumes that proximity to the subject or phenomenon under study is important, and that a reflective and carefully considered process of 'immersion in the terrain of study', enables significant access to both knowledge and fresh understanding. From this worldview, my own familiarity with HIV as a lived experience over the past three decades is a definite advantage.

The epistemological theories which justify this worldview come from different philosophers who have wrestled with questions of interpretation, understanding and meaning in human experience. In the following sections 3.6 to 3.9 I will explain how I came to identify the methodological approach known as 'hermeneutical phenomenology' as useful for my purposes. I will identify some of the key figures whose philosophical contributions justify my methodological approach.¹⁴⁹

3.6 Hermeneutical phenomenology as a methodological approach

When I began this research, I needed clarity about the main aims of this research. What is it that I am trying to do? There are two aims: firstly, I want to describe an experience; secondly, I wish to make sense of that experience - to explore the meaning(s) of it and make sense of it in the light of faith. This experience has at least one factor commonly shared by the participants, that of HIV infection, intimately experienced. This shared feature within a number of people's individual and varied situations, qualifies 'living with HIV infection' as a

¹⁴⁹ In regard to epistemology, I have relied heavily on Smith, Flowers and Larkin, who provide a guide to the theoretical foundations of what they call 'interpretative phenomenological analysis', in chapter two of their book (Smith et al., 2010, pp. 11-39).

human phenomenon. So, I wish to describe a *phenomenon*.¹⁵⁰ And for my description to be credible it is obviously important that I have access to as full a description as possible, from reliable sources. Wider society, and the church in particular, cannot know what living with HIV is like, if the phenomenon has not been described, or if it goes un-noticed, the people unseen, and their stories unheard.

3.7 Phenomenology – what is it like...?

Max van Manen states simply that “Phenomenology asks, what is this or that kind of experience like?” (van Manen, 1994, p.9).¹⁵¹ The philosophical starting point for phenomenology as a method of inquiry, or as epistemology, is most often attributed to Edmund Husserl¹⁵² (Smith, et al. 2010, pp. 12-16; Walliman, 2006, p.205; Lavery, 2003, p.3). Husserl proposed that it is valid to inquire into the *essence* of a phenomenon, and that the essence of an experience may be understood to have relevant and reliable meaning when described from the perception and mental processes of the person. Husserl asserted that acts of consciousness, as well as the objects of a person’s attention, can be explored in order to find the essential features of a person’s experience, as perceived by them, which may also “...illuminate a given experience for others too” (Smith et al. 2010, p.12). In this study, my expectation is that through inquiry into the particular experience of individuals, paying close attention to how they consciously make sense of their experience and ascribe meaning to it, I might also uncover something of wider significance for others (Smith et al. 2010, p.38).¹⁵³ According to Smith, Flowers and Larkin, Husserl has “...set the agenda for the attentive and systematic examination of the content of consciousness, our lived experience, which is the very stuff of life” (Smith et al. 2010, p.16).

¹⁵⁰ Creswell also includes an example of a phenomenological study by Anderson and Hull Spencer, which sought to describe the cognitive representations of disease amongst people living with Aids. Anderson and Hull Spencer are interested in the ways in which people ‘image’ their condition. It is an inquiry into how people make sense of their experience, and how that might impact upon health related behaviours, and their outcomes. It is an inquiry, firstly, into meaning. Secondly, in terms of outcomes, it hopes to learn something new which will inform clinical practice (Anderson E. H., and M. H. Spencer, 2000, in Creswell, 2007, pp.265-283).

¹⁵¹Max van Manen is emeritus Professor in the Faculty of Education, University of Alberta, and Distinguished Scholar at the International Institute for Qualitative Methodology. He is a leading expert in phenomenology.

¹⁵² Husserl (1859 – 1938) was a German philosopher, considered the father of phenomenology (Bunnin & Yu, 2009).

¹⁵³ For a summary of the philosophy of Husserl, see also Honderich, 1995, pp.382-384, 658-660; Bullock and Trombley, 1999, pp.645, 646, van Manen, 2014, pp.88-96.

Of equal importance for this study, is the 'reflexive move' necessary for such an attentive and systematic examination to take place. As Smith, Flowers and Larkin put it, "...adopting a phenomenological attitude involves and requires a reflexive move, as we turn our gaze from, for example, objects in the world, and direct it inward, towards *our* perception of those objects." (Smith et al. 2010, p.12). In other words, paying attention to the lived experience of others in an attempt to describe and discover meaning within that experience requires that the researcher pays close attention to and becomes aware of the influences upon their own interpretive efforts. As an inquiry that is open to that which is as yet unknown, and seeks an understanding of how we experience the world, it involves noticing the very manner of our watching, and the content of our thoughts, feelings and perceptions. More than this, it requires a move beyond watching towards an awareness of how we are affected, through our attempts at noticing and understanding. The reflexive turn assumes that our efforts actually constitute an involvement that changes us (Todres, 2011, pp.11, 31; Smith et al. 2010, p.35; Swinton and Mowat, 2009, pp. 34-36, 60). The reflexive move is an attempt to bring to consciousness and make apparent, the object of our attention through the sensed perceptions and meanings we have given them. I will return to reflexivity as a tool in this research below.

3.8 Hermeneutics – filters of interpretation in pursuit of understanding

My second aim – that of making sense of, or understanding the phenomenon, is an act of interpretation, reliant upon different people, who interpret the same phenomenon in different ways. It is an intersubjective pursuit (van Manen, 1994, pp. 11, 58). For example, when I ask someone to describe their experience of living with HIV, I am not only asking them to describe the moment of infection, or the event of diagnosis; I am also inquiring into their understanding and reflection upon these experiences. Therefore, the first locus of interpretation occurs within the person whose individual experience is being considered. They recall and retell, and as they do so they attempt to ascribe meaning. As will be clear in the following two chapters, making sense of an experience may not be a straightforward process, nevertheless there is an attempt at interpretation through recall and reflection, and speech. The second locus of interpretation rests with the researcher-investigator. As I hear the person describe and explain both the events and meanings that they hold in relation to living with HIV, and as I inquire further, I too am interpreting what I hear, see and

feel. I am making sense of what *they* share with me, and trying to understand what *they* mean, but my eventual understanding and the writing down of my understanding, will be *my* interpretation of what I think the other person means (Smith and Osborn, 2009, p.53). There is a further locus of interpretation, and that rests with any person who reads this study (Smith et al. 2010, pp. 41, 182 -183; Cresswell, 2007, p.179). A person who reads my words - my attempt to communicate events and experiences in *my* life, which at the same time concern another person's interpretation of a series of experiences in *their* life, - will be making *their own* interpretation(s). As Hans-Georg Gadamer¹⁵⁴ put it "when we interpret the meaning of something we actually interpret an interpretation" (Gadamer, quoted in van Manen, 1994, p.26).¹⁵⁵

There is a further important qualification: Each of the interpretations formulated and presented (or re-presented) in this study, by any of the persons concerned, are time specific. That is to say, they are interpretations which are made at a given moment in time, and even though they may be the product of much reflection, they cannot be 'person-defining', or claim a static 'fixed-ness' for all time (Walliman, 2006, p.241; Smith et al. 2010, p.27; Todres, 2011, pp. 27 -29). A person will very likely develop a new understanding, and propose a new insight, which leads to a fresh interpretation, over time. This is clearly the case in all human learning. We understand ourselves and the world around us, in different ways at different times. For example, a person who is diagnosed with HIV will almost certainly have a different understanding of the experience of living with HIV on day one, year one, to that which they have on day one, year five or year ten. It is not so much that the object of our attention has changed, rather that our perceptions and understandings in relation to the object have developed.

However, as I describe later, people do have experiences, the initial impact and meaning of which 'stays with them' over time. A given interpretation sometimes remains largely

¹⁵⁴ Hans-Georg Gadamer (1900-2002) was a German philosopher and student of Martin Heidegger. Also, of relevance is Gadamer's assertion that "Because human studies are caught up in a hermeneutic circle, it is inappropriate to demand objectivity and neutrality in human sciences." (Bunnin & Yu, 2009).

¹⁵⁵ In his interview with me theologian David McLoughlin recalled an exchange that he had many years ago with the moral theologian Herbert McCabe, OP. His anecdote neatly makes the point. McCabe had presented upon the possibility that Jesus had been a disciple of John the Baptist, making reference to scripture. This being a new idea to McLoughlin, he sought clarification and asked McCabe, "is your interpretation exegesis or eisegesis?" Sharply, McCabe replied "All exegesis is eisegesis."

unchanged over time. Some experiences in life leave a very lasting 'impression' upon us, and that impression, as an interpretation which holds a clear meaning for us, may never alter significantly. Meaning may stay with us, precisely because of the significance it once held, and still holds for us.¹⁵⁶

I do not accept that this approach to understanding and the variability of human interpretation equals a naive relativism. This does not need to leave us in a position where we can make no claims to knowledge, and claim that there is nothing 'true', and that everything is relative.¹⁵⁷ Rather, this approach accepts that the process of interpretation is an attempt at expressing something of what we know through living, and from within our being, that is also in relationship with that which is outside and beyond ourselves, and may be interpreted differently by others. The field of yellow daffodils means something different for the poet than for the over worked gardener, but there are still daffodils in the field. My approach accepts that human interpretation and meaning making is a creative work in progress that can never completely capture the whole truth of an experience, but can still reveal authentic meanings. The meanings that we attribute to experience very much depend upon where we are in relation to the given experience, and multiple interpretations are therefore always a possibility. We can strive to interpret and make sense of our experience, and come to knowledge, whilst at the same time accepting that there is always 'more' than we can know at this time (van Manen, 1994, pp. 16, 17, 31). This variability does

¹⁵⁶ As an example, there are many personal stories that describe HIV diagnosis itself as 'a death sentence'. For many, this interpretation has changed, especially with access to more effective treatments that help maintain or rebuild the immune system. For some, HIV diagnosis no longer means a death sentence. The meaning ascribed in the past, whilst still present as a memory, has been modified and changed over time to something more hopeful. For others however, not only can they vividly recall feeling the same way, but for them HIV diagnosis continues to mean a death sentence. The initial interpretation remains as powerful as it first was, and has not yet changed significantly. This was true for one woman who was a participant of one of the PC summer retreats where I heard her personal sharing. Despite the reassurances that she had received from doctors and counsellors, she remained convinced that HIV was in fact a death sentence. Her initial interpretation had stayed with her for some years, and had remained unchanged up to that point in the summer of 2009. Her interpretation was modified however, when she listened to other participants' stories of life with HIV. In particular, the stories of those who had been diagnosed 10 or 20 years ago, and who were evidently still alive, made a new interpretation possible for her. The meaning of HIV infection changed for her, as a result of her encounters during that weekend.

¹⁵⁷ There is a tension between the sceptical tendency towards claims of accessing truth that has any objectivity, which is inherent in hermeneutic phenomenology, and the truth claims of theology (Swinton and Mowat, 2009, p.73), which I will discuss later.

not exclude the probability that we can also uncover meanings, which have ongoing relevance, over time, and across cultures (Todres, pp. 30 -32).

So, the descriptions and interpretations presented in this study acknowledge that there is a quality of fluidity which pertains whenever we interpret experiences in search of understanding. The validity of the understanding, according to Todres (2011, p.24) is “in the way that it ‘carries forward’ meanings into new productive relationships in the future.”

Todres echoes Denzin and Lincoln above, when they say that the interpretive practices of qualitative research transform the world. As I commenced this study, this interpretive stance coincided with my aim to generate knowledge which gives rise to fresh insights, creative of new relationships and a deeper understanding within the body of Christ living with HIV: “to help human beings to become increasingly thoughtful” (van Manen, 1994, p.21). In the philosophical debates around how we come to know what we know, this acknowledgement of the interpretative human dimension in experience, with its limits and potentialities, is called ‘hermeneutics’.¹⁵⁸

3.9 Hermeneutics and phenomenology – a brief summary of developmental milestones

Most scholars attribute the beginnings of modern hermeneutics to Friedrich Schleiermacher (1768-1834), the protestant theologian, who applied the ‘art of interpretation’, or more accurately the ‘art of understanding’ (Palmer, 1969, p.86) to scriptural texts. He sought to grasp the meaning of a given text through consideration of the grammatical qualities of the text, combined with an appreciation of the psychological influences at work between the reader, the author, and the text. Citing the benefits of scholarly research, and the ability to appraise from a distance the influences of the social and cultural milieu in which the author wrote, Schleiermacher claims that it is possible to understand the meaning of a text, more fully than the original author himself. (Honderich, 1995, p.353; Jasper, 2004, pp. 83-86; Palmer, 1969, pp. 84-86).

¹⁵⁸ Anderson and Hull Spencer, in the literature review section of their study, provide an example of the appropriateness of using a hermeneutical approach in HIV research, when they quote the study of Turner, 2000, into the experience of loss for people with Aids. (Anderson and Spencer, 2000, in Creswell, 2007, pp. 268).

He also proposed the necessity of what is called the 'hermeneutical circle'. This is "concerned with the dynamic relationship between the part and the whole, at a series of levels" (Smith et. al., 2010, p.28). In order to understand the 'whole' of a text, it is important to attend to 'parts' of the text, and vice versa. A single word constitutes part of a whole sentence. The sentence can only be understood with each constituent word, and each word only has the same meaning in relation to other words arranged as part of the same sentence. Similarly, the individual sentences can only be understood in relation to the paragraph or chapter in which they come, and so on. This is of importance here, because it demonstrates that understanding another person's words and experience, can only be achieved if we take account of the relationships, not only between word and sentence, sentence and chapter, chapter and book; but also between the author, and the cultural and psychological influences of the time, as well as our own situatedness and the influences of our own time and place. (Palmer, 1969, pp. 87–97; Jasper, 2004, pp. 20–22). Crucially, it allows for the individual interpretation, or understanding, by the 'hearer' of another person's words and experience. According to Palmer, Schleiermacher sees "...the interpretive problem as inseparable from the art of understanding in the hearer" (Palmer, 1969, p.96).

Equally as important for my approach is Wilhelm Dilthey's¹⁵⁹ view, that meaning is that which is grasped by human understanding through the reciprocal interaction of the whole and the parts. Meaning arises out of the process of attention to, and in the midst of, the dynamic relationship between the whole and the parts. This also applies to the whole, and the parts, of a person's life (Palmer, 1969, pp. 118 – 122). The meaning of experience is always contextual and relational. For example, the meaning of the event of HIV diagnosis, reported so often as 'a death sentence' in the early eighties when there were no known treatments will probably differ from the meaning of diagnosis in the UK today, when access to treatment is usually available; or alternatively, from the standpoint of a person who faces deportation from the UK to a country where access to treatment is not assured, and the standpoint of that same person when they are granted 'leave to remain' in the UK after a

¹⁵⁹ Wilhelm Dilthey (1833-1911) was a German philosopher at the University of Berlin. He was concerned with Hermeneutics and he understood philosophy to be the systematic interpretation of human experience (Bunnin & Yu, 2009).

lengthy appeals process; or for a person with a strong social network of support and for someone without any friends, and so on.

Martin Heidegger brings hermeneutics and phenomenology together explicitly.¹⁶⁰ He disputed the possibility of any purely objective study of consciousness itself. To access the meaning of a phenomenon is an intrinsically interpretative activity. Methodologically phenomenology is a hermeneutic endeavor, historically situated, and always created from a particular perspective. In this view, it is not possible for the researcher to be a passive observer. In my introduction, and throughout, explaining my own situatedness within and relationship to the phenomenon and people at the heart of this study, and the very process of inquiry which I explain in this chapter, follow from this worldview.

For Heidegger phenomenology is the interpretative pursuit of the meaning of 'being',¹⁶¹ as being discloses itself through human consciousness in all its "facticity and historicity." (Palmer, 1969, p.127). Being human is an interpretive state¹⁶² wherein interpretation is "continuous and never final, and where the phenomenon are understood not explained" (Cohn, 2002, p.730).

Heidegger also insisted that interpretation is never pre-suppositionless. To each new situation, one brings prior experiences, assumptions, prejudices and preconceptions. These 'fore-conceptions' are inevitably present in a way that can pose an obstacle to interpretation, and require that we pay attention, not only to those that we can name at the start of a research process, but those that we become aware of as our attempt at interpretation is underway. (Smith et al. 2010, pp. 24-27). This awareness is important for myself as researcher, and for the reader of this thesis, especially in chapter six where I argue that commonly held 'fore-conceptions' result in myths that are obstacles to understanding the situation of people living with HIV today if they are not noticed.

¹⁶⁰ Martin Heidegger (1889 – 1976) was a German philosopher and student of Husserl.

¹⁶¹ Heidegger used his own German word 'dasein' to connote the fact, or actuality, the "...simply being there" of human 'being'. It is almost impossible to translate accurately in English (Jasper, 2004, p.104). It is a neutral term: "it does not commit us to viewing humankind as a biological entity, as consciousness... or as essentially rational....It is the 'there' or locus of 'being': without Dasein there would be beings, but no being as such." (Honderich, 1995, p.176). As such, he moves the consideration of the interpretation of phenomenon onto an ontological level.

¹⁶² "Life is relative, and it expresses itself in many forms; in human experience it is never an absolute." (Palmer, 1969, p.103).

In summary then, I think that I can claim to *know* what I present here, based in part upon the assumptions and worldviews, expressed within the twin philosophical categories of phenomenology and hermeneutics. The methodological approach arises out of the place of human being, where these two categories meet, and is called hermeneutic phenomenology. The hermeneutic-phenomenological approach¹⁶³ attempts to get as close as possible to personal experience, but recognizes that this inevitably becomes an interpretative endeavour for all those who participate (Smith et al. 2010, p.37). Important for the theological argument that I make in Part II, this means that whilst this study must be clearly prompted by and grounded in the accounts given by my interviewees living with HIV, a phenomenological approach allows me to develop an interpretation and theological analysis which goes beyond the faith-sense they have made of their own experience (Smith et al. 2010, p.186). It also means by extension, that the research presented here will be considered valid, or authentic, only insofar as I am able to convey meaning(s) that also find resonance with others (van Manen, 1994, p.11).

3.10 Methods - Towards Understanding

It is often stated in qualitative research, but especially in relation to the approach I am taking, that there is no clearly defined methodical system that must be slavishly followed. In fact, experts in this area warn that following a set number of techniques or methods is no guarantee of producing valid research (Smith et al. 2010, p.40; van Manen, 1994, p.34). Such a mindset is antithetical to phenomenology. Remembering the warnings at the start of this chapter about the danger of 'methodolatory', I have adapted methods from ethnographic and narrative research, and used those tools which are sufficient for this theological inquiry. Still, the techniques that have been used should be made explicit. Next, I describe the methods used to explore the phenomenon of living with HIV in the light, or darkness, of

¹⁶³ Hereafter, in this thesis when I refer to phenomenology, or to the phenomenological approach or attitude, I am referring to hermeneutic phenomenology. As I have described, hermeneutic phenomenology is a development from within the distinct philosophical disciplines and histories of hermeneutics and phenomenology. That there are philosophical and methodological distinctions, similarities and differences between: hermeneutics and phenomenology; and phenomenology and hermeneutic phenomenology, should be noted. A fuller consideration is both beyond the scope of and not necessary for the purposes of this study. For a discussion of the distinction between phenomenology and hermeneutic phenomenology see Lavery, 2003. For an introduction to hermeneutic phenomenology see Figal, 2012. An extensive overview of phenomenological approaches and methodological considerations is given in van Manen, 2014.

faith. These are the tools I have used to draw upon the interpretations of others, out of which I will develop my own interpretations, which I hope will deepen our understanding of what it means when we say that the body of Christ is living with HIV.

3.11 Interviews: selection and preliminary considerations

For this study I have used interviews with two distinct groups as part of the research process. The first are theologians and practitioners who have lived through, explored, taught, and written about HIV, in theological perspective, or are actively involved in some way in the pastoral care of those living with HIV. The purpose has been to generate ideas, or themes that could be explored, and to listen out for observations, and insights which could inform the research. A secondary purpose was to listen for questions and conclusions that either confirm or challenge my own pre-conceived hunches, ideas and beliefs. Most of these interviews took place at a very early stage in my research. As well as helping me to focus on aspects of experience and theological themes that seemed relevant to pursue, they were useful experientially in helping me decide upon the questions and approach that I would take when interviewing Christians diagnosed with HIV. Commencing this research I had not intended that these interviews would become a central part of the study. I had intended to use them as opportunities for background research. However, they shared with me some very important experiences that prompted me to think deeply about how people living with HIV are perceived which is important for the argument I put forward in Part II. I describe these interviews, the process of selection, the theological themes that emerged, and what I learned from them methodologically in the following chapter. Each interview was recorded and I made full notes with quotes and some questions arising following these conversations.

The second and most important group are Christians living with HIV. From the outset I have taken the view that Christians living with HIV are those best placed to speak with authority about what living with HIV in the body of Christ means. This assumption is shared by others. Mary Jo Iozzio (2008, pp. 7-8) has referred to it as the 'epistemological privilege' of people living with HIV. Vincent Leclercq (2010, p.5) writes that people living with HIV are "the 'experts,' the first-hand witnesses" whose experience needs to be heeded. This is not the same as saying that each person will be able to articulate the meaning of their experience in academic theological language; it is to say that through paying close attention to the faith-sense that they make of their experience rich theological seams of meaning may be

uncovered and explored. In the following chapters, I will describe how this assumption remained central to my approach as my research proceeded, not least following my interviews with the theologians. In chapter five I introduce this group of interviewees properly, and along with the argument I make in Part II the validity of this methodological approach will be tested.

For the interviews with those living directly with HIV, I have utilized a relatively small interview group, to allow for an in depth, careful analysis of individual experience. Spreading the research attention too widely, may also result in spreading our attention too thinly. As I hope is now clear, I consider it possible to gain valuable insights that will be both interesting and more generally informative, from this process of close attention to particular experience (Smith et al. 2010, pp. 29, 32, 38, 56 – 57, 202).

I used my contacts within the Positive Catholics community to select these interviewees, which is a type of ‘convenience sampling’ and is justifiable when gaining access to people who are otherwise ‘hard to reach’ (King et. al., 2019, p.62; Cresswell, 2007, pp. 125-129). With one exception each of the people had attended at least one Positive Catholics retreat weekend, within which very personal stories and feelings are shared within the relatively safe environment of a peer support group.¹⁶⁴ Given that this inquiry seeks to make faith-sense of living with HIV, I excluded individuals who were diagnosed within the past two years for two reasons. First, it can take months or years to come to an acceptance of an HIV diagnosis, and I wanted to invite people who had had time to reflect upon their experience. Secondly, I did not wish to run the risk of inviting a person who had not fully considered the implications of such a disclosure, even within the parameters of anonymized research, and who might subsequently regret such a decision for whatever reason.¹⁶⁵ There is an ethical

¹⁶⁴ Paul had contacted CAPS via email after meeting other Positive Catholics members and we had some correspondence. His circumstance and experience as a person living with HIV and Haemophilia prompted me to invite him to participate in this study.

¹⁶⁵ In pastoral ministry I have known people who have been diagnosed and have not spoken to anyone about their HIV status for years. There are others whose initial response, perhaps in a state of shock, or simply as a ‘cry for help’, is to tell numerous people with little thought or preparation e.g. family members, church members, colleagues at work, and later regret having done so. I have also seen people living with HIV who have been persuaded to speak in public or have their image used in public health materials who have later regretted doing so, either because they did not feel that the personal information they shared was received respectfully, or because their disclosure in speech or image led to their HIV status being known more widely than they had intended.

duty of care to any potential participant in research who is being invited to share deeply personal information.¹⁶⁶ Given the complexities of any disclosure of HIV status, to which I return in chapter six, I wanted to be confident that the person was giving fully informed consent. I made a judgement that two years mitigated the risk that a person had not had sufficient experience or time, to have thought carefully about the emotional, psychological and social implications of any disclosure. As this is an inquiry into the meaning of HIV in the context of a journey in faith, I invited people who I knew to have a demonstrable commitment to Christian faith. I considered it more probable that I would gain valuable theological insights from those for whom Christian identity and faith mattered rather than others who whilst being baptized and therefore qualifying as members of the body of Christ, had abandoned their faith or for whom membership of the church was unimportant.¹⁶⁷

Within these parameters I invited 10 people from varied cultural backgrounds, male and female, young and older, of diverse sexual orientation, recently diagnosed and long term diagnosed. As will be discussed in the following chapters, in part this choice was arrived at because I had not decided prior to these interviews upon a more specific focus within a particular community affected by HIV; for example, refugees living with HIV or gay men. Given this, I chose to include as diverse a group as possible broadly reflecting the demography of HIV in the UK, which enabled me to consider similarities and differences in these accounts. However, it is important to note that this approach aims to understand people with a particular perspective, without making a claim that they are representative of a population (Smith et al. 2010, pp. 48-51). Everyone interviewed is an adult over the age of twenty-one. Each interview was recorded and has been transcribed in full by me.

¹⁶⁶ With the exception of Paul, (simply due to the fact that we have not spent much time together), all of the interviewees at the time of conducting this research were my friends. Lisa Tillmann-Healy (2003) makes an interesting argument for 'friendship as method' in qualitative research, in which she offers a description of some of the complexities for research participants who were gay and others who were HIV positive, in regard to consent at different stages of research. These are similar issues to those that I am aware of because of the stigma attached to HIV and the fact that my interviewees were (and are) in friendship-relationships both with myself and other members of this group of interviewees. I return to her friendship as method later in this chapter.

¹⁶⁷ This would also be an interesting group to access to understand what living with HIV in the church means for them, in ways that would also bring fresh insight and meaning that could change the church.

3.12 Structuring the interviews

I have used a semi-structured interview process for both groups (Davidsson Bremborg, 2011). A sufficient structure to maximize the possibility of seeking an understanding of particular aspects of experience has been needed, in order that I did not simply end up with unmanageable amounts of data, or data unrelated to this study. A semi structured interview has provided a sufficient framework to align these conversations with the wider research project, and ensure that in each interview we are pursuing broadly similar questions and themes. At the same time it allowed us the flexibility to follow interesting threads of thought and reflection as they arose (Smith et al. 2010, p.57). I have sought a balance between open-ness to the experience of others, whilst at the same time being clear about the general context of inquiry.¹⁶⁸ The interview is after all a conversation with a purpose, informed by my research question (Smith et al. 2010, p.57).

I have been guided by Smith, Flowers and Larkin, who provide a helpful guide to the process and considerations necessary in preparing the schedule for the interviews (Smith et al. 2010, pp. 59-64). Drawing from narrative research approaches the interview questions for those diagnosed with HIV were designed as an invitation to share stories and reflections upon experience. The schedule of questions was tested out informally, with friends and colleagues. I will make clear in the following chapters how the first set of interviews with theologians informed the selection of questions used with the second group.

I have also been conscious that some of these interviews could easily touch upon sensitive issues, and provoke strong feelings and sometimes painful memories and emotions. I have felt reasonably confident, due to past experience, in my ability to stay with difficult issues and feelings, and I have given careful thought beforehand to how I might respond sensitively and with great care should this occur.¹⁶⁹ I have scheduled the interviews at a

¹⁶⁸ It is necessary to make choices as a researcher, whilst at the same time taking care not to close off avenues of meaning that may be important for the person being interviewed. My intention has been to remain open to discovery. As a basic example, I have not asked people to answer questions relating to their experience of HIV and the work place. Although this subject may be referred to in a person's retelling of experience, work place issues are not directly relevant to the questions of this research and would be unlikely to yield meaningful insights. I have attached the interview questions that I used as a template for those diagnosed and undiagnosed with HIV, as appendixes.

¹⁶⁹ Practically, I am and was aware of available resources that can be accessed, should a person reveal issues or challenges that might benefit from further help.

time and in a place that is private and comfortable, and I have given myself free time beforehand, in order that I might be calm, and best disposed in myself, without distraction, to pay careful attention to the person I am interviewing. Each person has been reassured from the start that the extent of their sharing is absolutely a matter for them. My intention has been to receive as a 'precious gift' whatever they wished to share with me, without pressure to share any more than they wished to.

Having gained approval for these methods from my supervisors, in accordance with the ethical guidelines of my university, each interviewee was given a briefing paper on the scope and uses of the research, and each signed a consent form in accordance with these guidelines.¹⁷⁰ Being diagnosed with HIV does not render a person incapable of making informed decisions about their participation in academic research. However, in *Emotional and Ethical Quagmires in Returning to the Field* Carolyn Ellis (1995) reveals how the conduct and eventual writing up of research, raises complex issues that can impact upon all those involved in the research process. Above and below in this chapter, and to a lesser extent in chapter five, I intend to make clear how the decisions I have made in conducting this research have been consistent with what Ellis has called "the ethics of care" (1995, p.94).

The first set of interviews lasted an average 90 minutes; the interviews with Christians diagnosed with HIV averaged 80 minutes in duration, which allowed sufficient time to engage "deeply with the participant and their concerns...to learn more about their lifeworld" (Smith et al. 2010, p.58) and to gather sufficiently rich data which is essential for an inquiry into the meaning of experience (Smith et al. 2010, p.56).

3.13 A collaborative concern building upon relationships

It is precisely because of my intimate connection with HIV as a lived reality, that I consider the experience to be significant for myself and others. It is also because of my own experience and understanding, that I have been committed to HIV ministry and the Positive Catholics ministry in particular. Previously established relationships of friendship and solidarity, through Positive Catholics, has enabled the interviewees to trust me with their stories. Lisa Tillmann-Healy (2003) writes about friendship as a research method which

¹⁷⁰ The participant information paper and consent forms are attached as an appendix.

resonates with my own characterisation of the approach I have taken.¹⁷¹ She maintains that “perhaps the most important aspect of this methodology is that we research with an ethic of friendship, a stance of hope, caring, justice, even love” (p.279). Friendship as method reflects a level of investment in participants’ lives, based in a “radical reciprocity” (p.280). In this way, this study can be said to have grown out of a prior, mutually expressed commitment between Christian people, who are members of the peer community that is Positive Catholics. To this extent, this is a collaborative endeavour, undertaken in a spirit of collective concern alongside others, who have given their time and shared their thoughts and feelings, in pursuit of a deeper appreciation of faith and HIV. Each interview has been undertaken explicitly with this understanding: whilst I, as researcher, am engaged in the study of *their* experience, it is also a mutual interpretive endeavor to find theological meaning in *our* experience, undertaken as a praxis of solidarity with each other, and the wider body of Christ living with HIV.

It is essential that research interviews are well conducted (Smith et al. 2010, p. 58). I have had some training in, and long experience of forming relationships, based flexibly upon Carl Rogers’ Person Centred Approach (PCA) (Kirschenbaum & Henderson, 1989).¹⁷² In my role as a group facilitator and leader in the Positive Catholics ministry, a PCA has informed my own practice. In my various roles and relationships, I have tried to model the skills and qualities of listening and empathic understanding, congruence, and unconditional positive regard (Rogers, 1986; Thorne, 2003, pp. 38-42, 50-52).¹⁷³ Applying these skills alongside pre-existing bonds of friendship and trust has enabled us to speak openly with each other. Acknowledging that we share HIV and Christian faith in common has enhanced the empathic understanding present during the interviews (Tillmann-Healy, 2003, p.282). Following PCA, I believe that these ‘core conditions’ and personal qualities facilitate meaningful conversation (Todres, 2011, p.26; Smith et al. 2010, p.55). A person who feels understood empathically and regarded positively - or as I would say in Christian terms, a person who is loved as they are - is much more able to speak honestly, and more able to reveal aspects of themselves to

¹⁷¹ Lisa M. Tillmann-Healy is Asst. Professor of Communication, Rollins College, Florida. In her later work (2015) reflecting a separation from her husband, she has changed her name to Lisa M. Tillmann. See footnote 166.

¹⁷² Carl Rogers (1902-1987) was an American psychologist and one of the founders of a humanistic approach to psychology.

¹⁷³ These are the so-called core conditions of PCA. Congruence is also sometime referred to as ‘realness’.

another, than when these qualities are not present in the relationship (Thorne, 2000, pp. 53-54).¹⁷⁴ So, my relationship with the interviewees has been helpful in the task of seeking together the meaning(s) of a shared experience.

Again, naming ‘friendship as method’ in this study is to recognize that an ethic of friendship arises from and because of pre-existing relationships. Tillman identifies how her research participants felt “heard, known and understood” (Tillmann, 2015, p. 297) as a consequence of applying this method. She reports how subsequently they were empowered to make new choices in their own lives and relationships. This sense of recognition and the possibilities for personal growth and new insight for her participants is one of the strengths of friendship as method (2015, pp. 296-301). With the exception of Paul, all the people living with HIV interviewed in chapter five have had similar experience of feeling seen, heard, understood and accepted by others, within the context of the Positive Catholics peer support ministry. This will be evident later, particularly in chapter nine. To betray the trust placed in me by my interviewees, or compromise these relationships would be unethical. I have regarded this research project as an “endeavor of friendship” (Tillmann, p. 299) within which those who participate might also grow in self-understanding and acceptance. Applying an ethic of friendship in this research, has meant that throughout, I have privileged the practices of friendship over any consideration of research outcomes.¹⁷⁵

3.14 The interviewee as expert in their own experience

Although I have been clear that the purpose of these interviews is not therapeutic in a counseling, psychological or personal development sense, Rogers’ core conditions as relational principles have been helpful in another way methodologically. PCA maintains a belief in the ‘inner locus of evaluation’ within each person (Rogers, 2004, pp. 119-124). When the core conditions are present in the counseling relationship the client can access their own meaning and find their own solutions. In counseling, this leads to a non-directive

¹⁷⁴ Brian Thorne is Emeritus Professor of Counselling at the University of East Anglia, and a leading expert on Carl Rogers work, especially in his combining Person-Centred Counselling and Christian Spirituality (Thorne, 2000, 2003, 2008).

¹⁷⁵ This refers not just to a respect for the individual person, which will be evident in chapter five, but also to what Tillmann (2015, p.292) refers to as research proceeding at the “natural pace of friendship.” As an example of a decision made by me consistent with friendship as method see footnote 180 below. Re: name change see footnote 171 and for a brief description of Tillmann’s original research project see footnote 166.

style on the part of the counselor. For the purposes of these interviews I have adapted this non-directive principle. It is not for me to impose my meaning, or presume to know or anticipate the meanings that another person may want to express (Smith et al. 2010, p.125). This has been especially important given that I already knew the people with whom I was speaking. I have had to put aside informally gathered prior knowledge of the person, in order to be open to what might emerge in the present moment. It can be tempting to anticipate what another is trying to express, especially during pauses or silences, with 'oh yes I understand', or 'I think you mean this or that don't you?' However, a rush to make sense of something by the researcher, may miss the point completely, or close off the possibility of accessing a deeper or more significant meaning that is trying to emerge from within the person. Silence is often fruitful, and pauses sometimes pregnant with meaning. It is a matter of attending upon the person, and having patience, in those moments (Smith et al. 2010, pp. 65, 67; van Manen, 1994, p.68).

Similarly, I have avoided interrupting with my own opinions or thoughts, or engaging in more ordinary conversation. The interviews have not been about me sharing my thoughts or my experience. My first purpose is to use the interview process as a way of "exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon" (van Manen, 1994, p.66), and as stated above, I believe that the interviewees are the best placed experts in their own experience (Smith et al. 2010, p.58), so I have asked open rather than closed questions.¹⁷⁶ As the interviewee has their own inner locus of evaluation, it is not for me to suggest, manipulate or impose, anticipate or direct, the person's meaning(s). My task is to create the conditions most conducive to enabling the other person to bring their own meanings to speech (Todres, 2011, p.28; van Manen, 1994, p.32).¹⁷⁷

¹⁷⁶ Questions such as 'You must have felt that God is punishing you?' are unlikely to be fruitful, not least because they may well result in a simple 'yes' or 'no' answer, which does not enable a fuller exploration of understanding. More importantly such a question is very suggestive of a direction that the researcher might wish the interviewee to take, and betrays pre-conceived assumptions.

¹⁷⁷ I have used open questions such as 'how would you describe your faith?' or encouraging questions: 'can you say a little more about what happened?', and 'How did this make you feel?', as prompts to aid exploration, with little directive intention, other than serving to invite the person to share their own experience in the way, and the words, that they want to (Smith et al., 2010, pp.59 -66).

I recognize that there is a power relationship that places the researcher in a position of authority and control during the interview (Cresswell, 2007, pp. 140-141). Not only are the interviewees becoming vulnerable because of the potentially personal nature of what they share, but also, as a willing collaborator the interviewee may desire to please the researcher, with types of answers that they imagine the researcher wants. Obviously, this is not actually what I want. Rather I am seeking the authentic thoughts, feelings and reflections of the interviewee, devoid of any manipulation that comes from me, whether intended or otherwise. It is almost impossible to be completely certain that my own presence has not negatively influenced or compromised the honesty and authenticity of what has been shared. However, the approach and techniques that I have described here, have acted in some way to protect against such manipulation, as well as the possibility of any exploitation of vulnerability. I will return to this non-directive style of interviewing in chapter five. During these interviews I have witnessed a degree of honesty and openness, that I feel privileged to have been allowed to share.

3.15 Insider participation – opportunities and limits

My own place as researcher is not remote from the phenomenon under study. As stated already I consider my own immersion in the terrain of study an advantage. However a question arises: How do I maximize the opportunities for insight and understanding that I have, by virtue of my own experience and involvement, without betraying the trust placed in me by members of Positive Catholics? Being a leader in the Positive Catholics ministry and community, I have privileged access to others. I have lead retreats, attended funerals, participated in group meetings, sat at hospital bedsides, and listened to those newly diagnosed. We have prayed together, laughed together, and cried together. In short, we, members of the Positive Catholics community have journeyed together, navigating the highs and lows of life with HIV as sisters and brothers in Christ. I have written records, photographs and artwork from these shared experiences. I also have access to data in the public arena, produced by CAPS volunteers, including CAPS 'Positive Faith' series of videos, including contributions from Lazarus and Cate who are both participant-interviewees.¹⁷⁸ Of

¹⁷⁸ The words of some interviewees who have participated in the *Positive Faith* short films are referenced in footnotes occasionally.

greatest significance to me, I have memories: of people, words, encounters and moments, that have stayed with me. My membership of Positive Catholics is an important part of my identity. It would be dishonest to deny that my own lived experience has informed this study, and foolish not to use my experience as a source of meaning.

As a participant member of Positive Catholics, I like every other member, am entrusted with and entrust to others, very personal information. Within an environment and atmosphere of mutual trust, a depth of sharing can take place. The principle and practice of confidentiality is essential when we are together. However, the requirements of confidentiality should not be equated with secrecy. It is unrealistic and unreasonable to expect people not to share with family members or friends, information or thoughts that in some way include reference to the words, stories and situation of others in the community. Confidentiality does not equate with secrecy. It does not mean that we take a vow of silence. The phrase 'in confidence' means that we have confidence that personal information will be respected as such, and treated as precious. We trust that our stories and experiences will not be shared outside of the community without the utmost care being taken. We are entrusted, and trusting.¹⁷⁹ Consistent with this practice of confidentiality, I have written about my encounters with others, and drawn upon their stories and experiences, as I recall them, from Positive Catholics retreats, group meetings and personal conversations, occasionally within this study. In the same way that permission has been sought when producing public documents, explicit permission has been given by any person whose experience is referred to directly by quote or description in this thesis. They cannot be said to have arisen by way of techniques of participant observation in the way that a researcher might carefully create opportunities to participate in the life-world under her study. However, they are the result of my participation, my being in the life-world of a community to which I belong.¹⁸⁰

¹⁷⁹ This care is necessary for very practical reasons. For example, if I was to speak about another person's experience in such a way that they were identifiable to someone that knew them, but may not be aware of their HIV status, the implications for damage to relationships and personal distress are, I hope, too obvious to need spelling out.

¹⁸⁰ Since I began this research formally, I have been aware of the opportunities to collect data through participation. During one weekend retreat at the early stages of study, I shared my hopes for this research with members of Positive Catholics. I also asked for permission to take notes during the course of our group discussions, for research purposes. Whilst people were encouraging and supportive, there was a clear suspicion that my new status as an academic researcher would compromise the dynamics in the group. Members looked for reassurance that my observing would not exclude my participating. I sensed an anxiety

3.16 Analysis of the interviews and data

The analysis of interviews in qualitative research is part of the process of identifying and grouping themes. In the following two chapters it will be very evident that both the interviews with theologians and those with people diagnosed and living with HIV generated a vast amount of richly descriptive experience and theological themes, and raised challenging questions about how one 'does theology' in the context of researching meaning at the intersection of HIV and faith. Following the interviews the challenge became one of managing, organizing, and interpreting these two data sets. In addition, I had also generated my own field notes and several initial attempts, short essays, reflecting upon aspects of these interviews theologically.¹⁸¹ My task was to begin to filter all this data and narrow the focus whilst staying true to my subjects' accounts, so that I might arrive at a manageable framework, within which further theological inquiry into meaning could proceed (Koenig, 2011, pp. 122-124). Beginning with Cate's interview I constructed a 'grid of themes' that emerged, and I repeated this process with the interviews with my principal subjects, adding new themes as they were mentioned and noticed by me, with relevant quotes, notes and questions arising (Braun and Clarke, 2006; Smith et. al., 2010, pp. 70-96). It soon became clear that far from narrowing my focus of inquiry this exercise simply generated an alternative format in which to view the same vast amount of data.¹⁸² Catherine Sexton

that members felt that my research task would take me away from the community. My presence as someone who studied others, threatened to compromise my presence in the group as someone alongside others. In order not to become a voyeur or covert exploiter of the experience of others, I decided after conversation with these members of Positive Catholics, not to attempt to 'remove myself' temporarily, partially, or otherwise, from my role in the Positive Catholics group. Very early on I decided to abandon any attempt to use our community gatherings as an opportunity for a type of formal observational research. As it turns out, it has not been necessary for me to be able to claim that I have studied the Positive Catholics community from the position of an uninvolved person. With hindsight, I now see the very suggestion as coming from a naïve and simplistic understanding of the value of objectivity in social research. There were also anxieties expressed as to the nature of any recording in writing, or by use of a voice recorder, that I might make, and the uses that this would be put to. There are ethical issues and legitimate concerns regarding the use of personal information, especially in regard to HIV. However, this anxiety was secondary.

¹⁸¹ For example amongst my attempts to pull at particular 'theological threads' from these interviews related to the research question were: an exploration of 'the body of Christ' drawing upon St. Paul's use of this imagery and it's mystical dimensions and actual relevance to the lived experience of my interviewees; understanding HIV and Aids as a 'sign of the times'; a consideration of religiously generated HIV stigma; and reflections on commonality in the experience of sub-groups within the cohort of interviewees living with HIV e.g. issues around gay sexuality for 4 men, and questions of divine retribution in the stories of 3 Africans.

¹⁸² I had soon constructed a grid of themes with quotes from interviewees ranging from 'Acceptance' through 'Christology' 'Grace' 'Healing' via 'Liminality' 'Scripture – refs to' and on to 'Vulnerability' and everything in between.

(2019, pp. 47-48) analysing data from interviews with Religious Sisters, describes a discomfort similar to my own, at this stage in research. The meaningful significance within these interviews seemed to be getting lost rather than being found through my attempts at codification (van Manen, 2017). Breaking the interview material into categories felt like a kind of interpretative shortcut that paid insufficient attention to each person's story as a unique text to be 'imbibed and savoured' and pondered theologically. Using this method as an attempt to categorise themes was not actually helpful in my process of discerning which 'theological threads' to focus on. What was common across all of the interviews was the experience of HIV as an experience of intense suffering, which is central to this thesis and to which I will return in the following chapters. However, this attempt was not futile because it was an exercise in paying close attention to each transcript, and began a process of reading and re-reading, that continued throughout the period of completing this study (Smith et. al., 2010, pp. 82-83). I return to my attention to the texts as a type of contemplative inquiry below (Sexton, 2019, pp. 47-48).

3.17 Reflexivity and clarity of voice

One reason for qualitative researchers to employ a method that categorises interview data transparently is to counter the criticism that qualitative research cannot be trusted because the 'subjectivity' of the researcher may interfere with claims to 'objectivity' (Koenig, 2011, pp. 124-126). Above I have justified my own proximity to this research and explained why I consider my closeness to both the phenomenon under study and these interviewees an advantage. I am making no claims to 'objectivity' per se. However, that the evidence I present in this study is a reliable and accurate description of my interviewees experience must still be demonstrated for my claim to represent their voices to be credible. The validity of my argument, will depend at least in part upon how my closeness to the study, and my awareness of how that has influenced both the process of research and any meanings or conclusions I draw, is apparent. That I am conscious of the biases, values and experience that I have brought to this study, and present my awareness sufficiently in this text, is the application of the reflexivity so necessary to phenomenology described above. (Cresswell, 2011, pp. 243-244).

Interpretation of experience is a complex matter. To grasp the essence of something according to van Manen is both "easy and difficult" (van Manen, 1994, p.77). He makes the

point well when he uses the example of time. Each of us knows about time. We live in time. We regulate our lives by it. We reflect on time past and anticipate time to come. Who amongst us does not have an understanding of time? However, if someone asks, 'what is time' who would not find it difficult to describe? It is this challenging task of putting into words the meaning of something that is at the heart of phenomenology (van Manen, 1994, pp. 32-33; Cresswell, 2011, p.157). As van Manen puts it, to undertake this kind of research is to "be involved in the crafting of a text" (van Manen, 1994, p.78). As I have crafted this text my own reflexivity in each chapter to greater or lesser degree, (along with 'thick description'), is included so that my own interpretative process is transparent; the integrity of the interpretation and meaning of my interviewees' experience is respected; and the reader can have confidence in their interpretation and any meaning that they arrive at through this study. Consonant with Tillmann-Healy's ethic of friendship, the task of writing has challenged me to maintain "care for [the] interviewees voices...the human phenomenon...being expressed...to care for how [my] own voice as writer reveals, conceals and co-creates, and to care for [the] reader as part of the ongoing conversation." (Todres, 2011, p.44).

So, my writing is both a description of the research process, as well as the outcome of my research. It is through my words that the description and interpretation of my own and other people's experience will be offered to the reader. It is upon these words that this study will stand, meeting or failing the test of credibility and validity. I have referred above to Husserl's reflexive turn which justifies epistemologically the attention to perception and consciousness. Much of this chapter has been concerned to make explicit the epistemological reflexivity that underpins this study. Questions related to my own worldview, and the assumptions I have made, or tried to avoid making; where I position myself, and why I have chosen the approaches and methods that I have, are examples of epistemological reflexivity (Swinton and Mowat, 2009, p. 60).

3.18 Reconciling social science methodology and theology

Qualitative methodologies have been used many times to measure the effect of religion, faith and spirituality, in the lives of people living with HIV (Pargament et al. 2004; Ironson et al. 2006; Kremer et al. 2009; Szaflarski, 2013; Kendrick, 2017; Rubtsova et al. 2017; Doolittle et al. 2018). As this inquiry is intended to find theological meaning within the experience of

living with HIV, it differs from social science studies using similar qualitative methods to assess the impact of faith, spirituality or religious belonging, upon a person's mental health, general sense of well-being, quality of life, or their adherence to medication and so on. This study is firstly theological. Theology takes priority over any social science methodology (Swinton and Mowat, 2006, pp. 88-91).¹⁸³ Whilst hermeneutic phenomenology provides a methodological framework that justifies the methods I have employed to access knowledge, the inherent skepticism of the interpretive worldview is insufficient epistemologically, to justify the claims and arguments that I make in this study (Swinton and Mowat, 2006, pp. 75-77). A phenomenological approach has taken me so far, but to go more deeply into the faith-experience and seek fresh theological insight is to go beyond the limits of these methods and requires the application of the resources of faith: revelation; scripture; tradition and prayer. Whilst academic theology includes and proceeds by way of intellectual reasoned argument, the 'epistemological' basis for theology is not to be found in hermeneutics or phenomenology. I want to be clear that the justification for my claims to know what I present in this thesis is based in the faith shared between myself and those I have interviewed. Whilst narrative and ethnographic research methods have been used to ensure rigor and lend credibility to my research, the methods have been applied within the context of Christian faith in pursuit of theological meaning.

3.19 Keeping faith with methodology

Bernadette Flanagan (2014) argues that when researching spirituality attentiveness to how the Spirit is at work within the research process can be useful. This resonated with me. In a way similar to how reading Tillmann-Healy's (2003) method of friendship helped me to name aspects of the approach I have taken, Flanagan's article helps me to name aspects of spiritual practice within my methodology. My faith and that of my interviewees living with HIV has been foundational to the process of research. In Part II I will name a spirituality that emerges from the lives and stories that my subjects have shared with me. Here I make

¹⁸³ Swinton and Mowat (2006, pp. 82-91) put forward a complex argument from Christology to assert the 'logical-epistemological-precedence' of theology over social scientific methodologies. Pattison (1986; 2007a) argues for the 'utmost relevance' of the social sciences within practical theology but warns that the pastoral theologian should be clear about the limits and scope of how the social sciences have been applied so that aspects of these disciplines are not exalted to a position of importance within theology that they might not deserve. This chapter is explicit about how the qualitative research methods have been applied to my research in the service of theology.

explicit how my faith and attentiveness to the Spirit has assisted me throughout my research process.

The worldview that I and my interviewees hold comes from Christian faith and belief in a Triune God. Faith has not been set aside in the interviews, for example, but has been intrinsic to each conversation, not just in regard to the subject matter, but also to the manner in which each interview was conducted. For my part I prayed before each interview, that my listening might be guided by the Holy Spirit. All but one of the interviews commenced with an acknowledgement that what we were engaged in was founded in a belief that Christ was present with us, and in faith that the Holy Spirit would in some way guide our conversation.¹⁸⁴ This appreciation of our meeting as a moment in a shared journey in faith was not an imposition, much less directive or manipulative on my part, but reflects the relationships that existed prior to these interviews, and arose naturally; that is to say it was not something that I had intentionally planned in preparing for these interviews. The naming of these conversations as grounded in faith acknowledged the dignity of each of my interviewees as a sister or brother in Christ, and that our time together was in the service of both God and others, undertaken within the context of openness to whatever new word God might reveal through us.

Methodologically, this Christian faith also means that in my worldview Christ is embodied in those who follow Jesus in a particular way. God is present in them, because they are created in God's image and likeness, and as baptized Christians they are inhabited by and expressive of the Holy Spirit who moves in their lives and animates their being.¹⁸⁵ This goes beyond the claim that these people are the experts of their own experience. My assumption is that divine revelation may happen through them. The Word of God is embodied in them in some way.¹⁸⁶

¹⁸⁴ In several of the interviews this included a very short prayer invoking the Holy Spirit, and in others it was a simple acknowledgement that Christ was present with us: 'where two or three are gathered in my name I am present' (Matt. 18:20) I did not know Paul well enough, having never met him in person prior to the interview, so I did not presume to impose any 'faith-framework' upon our time together, beyond that stated in the participant information document.

¹⁸⁵ Acts 2:38; Romans 8:10-11.

¹⁸⁶ 1 Thess. 2:13

Prayer has been important throughout the research process and has been most helpful in those times when I have felt overwhelmed. Following both sets of interviews, as I will show in the following chapters, I was faced with a number of possible theological avenues that I might have proceeded along. Pursuing this or that avenue often left me feeling that there is little new to be added that has not been written elsewhere already. For example, the issues of inclusion and exclusion from the body of Christ, common to each of my interviewees, led me to explore what it means when we say that 'all are welcome' in the church. Such a question applied to this research would lead to the ways in which people living with HIV are excluded because of HIV stigma and all that attends it. However, HIV stigma has been written about often. It is impossible to write about HIV theologically and not consider HIV stigma. But, it felt to me that I would be revisiting old ground; travelling along that particular thematic avenue led me to a rather familiar cul-de-sac. Similarly, theology around issues of inclusion and exclusion within the body of Christ is already covered extensively, not least in regard to other marginalized groups, where the limits of ecclesial scriptural and theological hospitality are tested. I gained knowledge for myself pulling at these theological threads, but remained uninspired. The hunch that motivated me to commence this research persisted; I often felt that nagging feeling that there was something more, something that could be expressed in new ways, within the text of my subjects' experience that I had yet to grasp.

Flanagan (2014) draws upon the traditional practice of 'Lectio Divina' and offers the four steps of reading (lectio), reflecting (meditatio), seeking guidance (oratio) and being open to mystery (contemplatio), as means to turn the research question into a divine question. In chapter four, the overarching question, 'where is God in all this?' is just such a turn. The question of finding theological meaning begins by asking where is the divine in the midst of HIV and Aids? Such an explicitly prayerful approach consciously seeks the divine Spirit within the research process. In this study, the Holy Spirit has been acknowledged and invited in, as a partner in the hermeneutic interpretive endeavor.

Being open to mystery and waiting in a place of 'not-knowing' will be evident in the next two chapters, and is intrinsic to many of my interviewees' experience in Part II. Lest I am misunderstood, this openness to mystery and patient waiting is often as not an uncomfortable, disorientating, and confusing state of being. I am not inferring a type of

calm detachment from the phenomenon under study, or the research process. I had to resist the temptation to grab at a doctrine, or an external theological category, even a common experience in my interviewees' stories, in haste, in order to feel more academically or intellectually secure. As Flanagan (2014, p.136) says the researcher is "challenged to become less and less controlling of the conclusions of the research, and more and more committed to a contemplative stance towards the meaning of the findings." My first task was not to find reasons for an argument, but to discern and uncover the spiritual and theological insights embedded in my participant's stories. To make the claim that I am speaking with others and not only for myself, with authenticity and integrity, has meant setting aside any academic impatience or applying analytical methods reductively. At times like this, when I doubted that I would ever uncover fresh insights, I handed the problem over to God in prayer, and waited on the Spirit.

Like the first step in *Lectio Divina* I have approached these texts with a careful reading and re-reading (Hall, 1988, pp. 36-38; Salvail, 1996, pp. 44-46; Bianchi, 1998, pp. 52-53). I have returned again and again to the recordings of my participant interviewees lingering over all the sounds, tones of voice and rhythms of speech, and recalling the feelings that were present (Gilligan, 2003). I found that words or phrases from my interviews stayed with me. Joseph's words (in chapter eight) 'I became pain' are an example. Sometimes sitting quietly, and more often as I went about my day to day business, I pondered this and other phrases, listening not only to Joseph's words but waiting to be drawn by the Spirit, receptive to the voice of our Lord who wishes to speak to us (Bianchi, 1998, pp. 43-45).

Throughout my research, from the interviews to the writing of this thesis, I have approached the task of understanding experience and discerning theological meaning within the lives of Christians living with HIV in the body of Christ, prayerfully. As Pattison has noted, "Contemplation, rumination, reverie, hovering attention – and perhaps even hovering inattention – need to be valued more highly as main constitutive methods" in practical theology (Pattison, 2007, p. 285).

3.20 Summary conclusion

In this chapter I have outlined the epistemological theory and argued for my adaptation of the interpretative phenomenological methods used in my research. I have explained the approach I have taken to the preparation, conduct and analysis of the data generated in the

interviews and how my faith and that of my subjects has been a motivation and source for this study. This is the first of three chapters concerned with methodology. In the next chapter detailing my interviews with theologians and following with Christians diagnosed with HIV in chapter five, the application of this methodology will be described in detail. As a description of my research these three chapters proceed incrementally from theory, through application, towards the argument I make in Part II of this thesis. Insofar as this thesis is an encounter with HIV, I intend to move gradually from the mostly theoretical consideration of how I approached research in this chapter; via the sometimes bewildering process of sifting rich theological data generated in the interviews; towards an encounter with those whose stories and lives are the principle texts through which I have sought theological meaning.

Chapter 4. Interviews with Theologian Practitioners

4.1 Introduction

In the previous chapter I made the case for the theoretical methodological approach that I have taken. Here, I present interviews with several theologians that were important in my preliminary research. These conversations informed both the methodology and the theological arguments that I use in this thesis. The manner of and reasons for the approach that I took; the key learning points that encouraged me in terms of the methodological approach I have employed; and those emerging theological themes that have been most influential for the argument I will present in Part II will be evidenced.

Each interview was concerned with the overarching theological challenge summed up at the start of my interview with Kevin Kelly who asked *“Where does God fit in to all of this?”* He exemplified what I am calling ‘theological humility’ as he continued:

“That’s the basic issue isn’t it? Probably one that you could answer better than I could.”

(Kevin Kelly)

I highlight this at the outset for three related reasons: Firstly, the ‘humble stance’ of each person interviewed influenced the quality of our conversations and afforded me a sense of equality which I had not expected, but from which I learned. Secondly, it is indicative of an approach to theological research which assumes that there is more to be revealed; each person referred explicitly to the limits of their knowledge and openness to new learning, even in the course of these interviews. Third, what Mary Jo Iozzio (2008, pp. 7-8) has called the ‘epistemological privilege of people living with HIV’ is evidenced both in the respectful way that they related to me, and through the stories they told me. The centrality of experience when undertaking theological research into HIV will be a repeated thematic thread throughout this chapter.

I will not give equal weight to all the theological themes mentioned in the course of these interviews; to attempt to do so would be to try to cover too vast a range of topics, and is beyond the scope of this thesis. One of the reasons that inquiry into the phenomenon of HIV remains interesting is because there is an extraordinary overlap of theological challenges across a variety of human situations. However for the individuals who have contributed to this study, including the people living with HIV, the particular concerns and questions, and

conclusions where they are arrived at, always reflect the personal situated-ness of the interviewee: that is to say, their own personal experience and journey in faith; and the context of their exposure to HIV as encountered in their own lives and the lives of others. This may seem to state the obvious, but provides an explanation for the editorial choices I make in recounting the issues discussed in these interviews. I consider the personal dimension of HIV in the lives of each of my interviewees as described below to be as important, and arguably more relevant for this thesis, than any doctrine mentioned, because their accounts illustrate how, so often, an encounter with HIV can be a type of conversion experience.

Following the rationale for approaching these theologians, I provide a short description of each individual and relate some of the theological content from each interview. It will be clear, that as I began this research there was a vast choice of possible theological themes that I might have pursued. So that I do not misrepresent these interviewees it is important to say that unsurprisingly, each person made reference to the range of theological issues with varying degrees of emphasis.¹⁸⁷ In what follows I am not claiming to give a full account of the interviews, much less represent the totality of the theological views of the individuals. What I present is an original contribution to public knowledge, and the interviews with Kevin Kelly and Sebastian Moore are, to my knowledge, the last recorded interviews that they gave. I will not debate their statements in detail in this section. Rather, I intend to reveal the richness and scope of the data that was generated. What follows is an account of the conversations we had from my perspective. As such, this chapter describes how the methods I used were applied and the results of inquiry at this stage of research, including a sense of some ambiguity and confusion within the process of theological inquiry itself. At the conclusion of this chapter I hope the reader will understand the choices I made and how these conversations shaped the further direction of research; what I now understand to

¹⁸⁷ These established theological challenges include, but are not restricted to: The nature of God in the face of human suffering; HIV stigma; healing; links between sex, disease, and sin; mortality; human sexuality generally and gay sexuality in particular; Christian attitudes to the body; structural sin and social justice; gender inequality and the place of women in society and church; patriarchy in society and church; the nature of the church as the body of Christ especially in regard to issues of exclusion and inclusion; pastoral care and ministry for people living with or directly affected by HIV; the role of the church in public health; and the challenges of theological education in regard to all of the above.

have been most methodologically important; what I retained as theologically significant for this thesis and what I have discarded.

Many of the theological questions raised in this chapter will not be carried forward explicitly. Nevertheless, I think they are worth including in this thesis at this point. Although not the very start of my research journey, I was at a place that might be described as a cross-roads, or more honestly, a spaghetti junction of theological signposts. As already stated, I want to convey a sense of the various possible theological routes I might have travelled. Second, these accounts and the questions and insights raised are of theological and academic value in their own right.¹⁸⁸ Together these accounts, like pieces in a puzzle, construct the wider landscape of inquiry and theological context within which this study is set. Third, if the process and task of communicating theological research can be understood as a type of shared journey in faith, consistent with the understanding of this study as a shared interpretative endeavour, I am consciously inviting the reader into this sometimes bewildering theological space of multiple choice and numerous questions. I trust that the conversations below will prompt further questions for the reader just as they did, and still do, in me. I will describe how these conversations influenced me to maintain a stance of further inquiry which remained very open to the stories that I would hear later from people living with HIV, rather than one which could have fore-closed further research within a doctrinal category. A bit like showing the workings-out of a mathematical problem, these accounts will help the reader to understand how I have arrived at the theological arguments that I put forward later.

This chapter situates my thesis within a wider community of theological inquiry and provides evidence that justifies my approach. It also serves as a kind of bridge between the background and theory of previous chapters, and the heart of this thesis, which is to be found in the accounts of lived experience and faith that I have heard from people living with HIV in the next chapter and Part II. I will conclude with a summary of the key learning points that I have taken from these interviews.

¹⁸⁸ Not only are these accounts useful in terms of the questions they raise, but as two of these theologians have since died, the accounts may be of future relevance for other research. In particular my interview with Sebastian Moore was the last recorded interview he gave, and includes reflection upon experience that I do not think is revealed elsewhere in his published work.

4.2 Rationale

As I began my theological research, it seemed sensible to approach more experienced theologians with a personal and academic interest in the area of HIV and Christian faith. I began by contacting theologians with whom I had already had some previous contact.¹⁸⁹ In the course of conversation about this research, with these theologians, I was referred to Christina Beardsley and Ijey Ajibade whom I had not met previously. With the exception of James Alison, each of these interviewees was based in the UK, which made a face to face meeting practical.¹⁹⁰ Each interview was digitally recorded.

My continuing active involvement with CAPS also motivated each person to give me their time and attention. These connections are worth noticing insofar as they smoothed my way as a researcher, and I received very generous hospitality from each of the people I interviewed. Sometimes conducted over a meal, the interviews lasted an average 90 minutes, and took place between autumn 2011 and spring 2012. I provided each person with the same set of questions that would guide these semi-structured interviews beforehand.¹⁹¹ I included a final question in the interview, which invited the interviewee to speak 'off the record', about anything that they wanted to say, but that they did not wish to be recorded or repeated in this thesis or publicly in other ways. None of those interviewed availed of this option. Only Christina Beardsley reserved the right to check beforehand that

¹⁸⁹ I was fortunate to know many of the theologians interviewed, having previously met them on HIV related projects or in the context of pastoral ministry. For example, David McLoughlin attended a training event for clergy that I facilitated in the mid-nineties. I first met Kevin Kelly and Julie Clague at a weekend theological symposium in Dublin; the first organised by the Caritas Internationalis (CI) Working Group on AIDS. Martin Pendergast and I attended from CAL. It was January 1994. The reality of HIV and AIDS as an enduring global pandemic was clear. Theologians and practitioners from Europe, Great Britain, Ireland and the USA, gathered for theological reflection upon HIV in the light of faith, in the hopes of establishing theologically sound Christian responses. A series of regional theological consultations held by CI in Africa, Asia, North America, Latin America and Europe followed. Enda McDonagh, Emeritus Professor of Moral Theology, Maynooth, and Ann Smith, were also present. This was the first occasion McDonagh shared his initial reflections that later became his influential 'Theology in a time of AIDS'; first published in the Irish Theological Quarterly. McDonagh's recognition that the pandemic was a '*kairos* moment – a time of God's special presence and summons' has been repeated often in the literature (McDonagh, 1994, 2007). As Cafod's lead officer on HIV strategy, Smith later developed the HIV educational tool 'The HIV Problem Tree' (Smith & McDonagh, 2003, p. 56) which was used in training throughout the world, to visually describe how HIV is a personal and medical issue and one that has both causes and consequences rooted in wider structural and social contexts. This is one example in which the theological reflection and sharing undertaken during the weekend had a focus and intention upon theology practically applied. See footnote 214 for additional detail relating to the Dublin meeting.

¹⁹⁰ James Alison was living in Brazil at the time, and our interview was conducted via skype.

¹⁹¹ Appendix 3.

anything published beyond this thesis¹⁹² would not conflict with her role and responsibilities as an NHS Chaplain.

Some of the interviewees had prepared notes before we met which they gave me. I recorded each interview and made subsequent notes. I have found that through listening to each interview repeatedly, throughout the whole period of my research, I have often heard something in a fresh way or noticed something for the first time that I had missed or paid too little attention to previously. I have found it necessary and beneficial to return to both my notes and the recordings multiple times.

When I commenced these interviews I had no preconceived category of ecclesiology, or soteriology, spirituality, Christology, moral or pastoral theology; much less the work of any one theologian that would provide a theological structure or direction, around which I might pursue the research question. However there were broad theological areas of inquiry with which I was occupied at the time, particularly those related to suffering and sin within the context of HIV.¹⁹³ I was also thinking about Matt. 25: 31-46 as a baseline Christian obligation, and what is meant when Christians say that we encounter Christ especially in those who are poor and in need. Those 'hunches' derived mostly from my experience in CAPS ministry, which motivated me to commence this research, described in previous chapters, were also on my mind at the time. Although I intended to maintain a stance of sufficient neutrality so that my own preoccupations did not steer the interview process, or negate the purpose of asking open questions, implicitly, these interviews were opportunities for my own nascent theological and methodological hunches to be tested. As I describe below I did share my own thoughts with the interviewees, but I was careful to share them tentatively; as the open questions that they were rather than conclusions.

These interviews comprise one method that I used to begin my research. I had three objectives in mind:

- To understand from these experienced theologians the main themes already established within academic theology and identify gaps in my knowledge.

¹⁹² E.g. an article in a journal.

¹⁹³ I had recently read Allen, P.L., 2002. *The Wages of Sin; Sex and Disease, Past and Present*.

- To listen out for and identify any new theological threads or questions.
- To practice my semi-structured interview method and use the experience to inform the forthcoming interviews with people living with HIV.

4.3. Interviews with theologians and practitioners

Ijey Ajibade is a Church of England priest. She was involved in pastoral ministry within London and at the Anglican Southwark Cathedral. She was adamant that all clergy in London ought to have some awareness training on HIV, particularly because half of the population of people living with HIV in England and Wales at that time were living in the Capital. To this end she had been involved in devising training for clergy in Southwark Diocese. Whilst HIV remained important to her, she explained that she was now more actively involved with the related issues of LGBT rights, especially within Africa.¹⁹⁴ She is aware of how the marginalisation of gay people, and others, including sex workers and drug users, not only makes them more vulnerable to HIV infection, but also represents a failure of the churches to *“come alongside people”* which I refer to again below. Because of her background within the Pentecostal tradition, she highlighted the ways in which some theologies can gloss over the *“real struggles”* that people undergo. In those *“big glamorous...churches...where ‘everything’s wonderful’ kind of talk [is] preached...human life at it’s most frail is sometimes lost.”* This insight led me to research so called ‘Prosperity Theology’ in the context of HIV.¹⁹⁵ Ijey also contributed to the CAPS ‘Positive Faith’ project in 2017.

James Alison is a Roman Catholic priest and systematic theologian. He was raised in an Evangelical Anglican family and became a Catholic at the age of 18. He lived as a member of the Dominican Order of Preachers between 1981 and 1995. At the time of our interview and today James works as an itinerant preacher, lecturer and retreat giver. He has published several books which have brought the work of René Girard to a wider audience, and his theology is from his perspective as an openly gay man. James was more actively engaged in ‘HIV activism’ and pastoral ministry with people living with HIV directly, in the 1980s and 1990s. He attended the ‘Spode Conference’¹⁹⁶ and later wrote the first Catholic Truth

¹⁹⁴ See Ajibade, 2016.

¹⁹⁵ See Barnes, 2013.

¹⁹⁶ The first Roman Catholic HIV Conference in the UK ‘The Catholic Church and AIDS’ held at the Dominican Spode House in 1986. See fuller account in introduction.

Society pamphlet on 'Catholics and AIDS' in which, he told me, the use of condoms as preventative of HIV infection was included as morally licit, without attracting any controversy at that time. He distinguished between the issues as he encountered them in the past and those of today: *"The issues were really emergency ones, accompanying people who were dying trying not to be frightened oneself and trying to help other people not to be frightened, as well as a huge privilege being alongside people who were beginning to be able to tell stories in the very short time that they had to be able to formulate them. I imagine that now the questions are much more about living with something and thinking through what it means to live and relate to other people and love and so on, which is vastly healthier and much more interesting."* James remembers the early years as traumatic, and how *"HIV and Aids has forced a degree of honesty in areas of discussion that were simply not available to theological and Christian discourse before...it has forced us to be much more honest and made honest conversation much more necessary, with all the complexities that involves, because that involves facing up to how we fool ourselves, how I fool myself. It's difficult to be honest and transparent about how one relates and how one copes with our feelings, and our sexual urges and so on."* He referred to his encounters with HIV as moments of Grace: *"My understanding about Grace, God being deathless, the resurrection and our bodiliness, were all very deeply impacted by particular relationships with particular people at that time, which has continued since. Once you are able to look at mortality with love, that kind of opens things up."* In chapter six I return to how James' experience helped him to be more honest about his sexuality and how in accompanying friends who died of Aids, he lost the fear he had of death.

Christina Beardsley is a Church of England priest and, at the time of interview, the lead chaplain at London's Chelsea and Westminster hospital, which since the 1980's has included one of the main HIV treatment centers in the UK, including a dedicated ward for in-patient care. In this role her pastoral ministry involved meeting the needs of people living with HIV and their friends and families, within a UK context. She listed three broad theological and pastoral challenges as we began the interview. First, healing, which she distinguished from 'cure', and can only be approached within the context of enduring HIV stigma, and leads her to *"the whole notion and imagery of stigmata and having to live with wounds."* Second, Christina raised the big existential question of suffering, which she called *"the problem of*

evil.” Third, she spoke about the need to reflect further upon HIV in relation to emerging theologies of the body and human sexuality, which she expanded upon. She talked about how the use of complimentary therapies in the first decades of HIV and Aids could teach us about the need for a *“spirituality that is embodied”* and more *“holistic”* approaches to both spirituality and healthcare. Christina’s list of unfinished business included the role and place of women in the Church, and the inclusion of gay people. She considered the phrase ‘the body of Christ has Aids’ still has the power to disturb and challenge Christians: *“Doesn’t it just focus that whole thing about purity...the body of Christ, especially in the sacramental tradition is this very pure bread, the host, so I do think there is this shock factor...so if we are to be one body....there is no separating off...I think it is an extraordinary phrase...most people want to split, want to separate, want to keep the body pure, and it’s a very challenging phrase for all of us.”* Lastly, Christina spoke about how we do theology in a time of HIV: *“The writing has to come from people living with HIV. It’s got to come from the people and their lived experience.”* Below I will say more about how Christina’s encounters with HIV challenged her in terms of her ministry as a priest and caused her to reflect upon her own prejudices.

Julie Clague lectures in Catholic Theology at Glasgow University. She has been a theological consultant to Cafod as a member of the HIV Advisory Group; the Scottish Catholic International Aid Fund, the official aid agency of the Catholic Church in Scotland; and the Ecumenical Advocacy Alliance (EAA) and World Council of Churches (WCC). Julie recognises that serious consideration of HIV in our world raises a great number of issues for the church. Not only does HIV raise specific questions that challenge a range of existing theological positions, but it causes a reappraisal of the theologians methodological approach: *“People often focus on one thing or another, they might talk about, theology of sexuality, or embodiment, or ideas of sin, but actually, for me, I think it reconfigures the way we think about all of theology. I don’t think there is any bit of it left untouched...there is nothing really that is not a sensible conversation to be had in the world of theology, that is not relevant to, or made more relevant, actually, by HIV in my view.”*

As a lived reality HIV impinges upon all the fundamental aspects of what it means to be a person: *“The whole of human experience is embodied in the experience of what it is to be a human being living with HIV, or a community of people in which there are people with HIV.”*

So, the questions of health, healing, loving, living, dying; the big questions that we all have to not only live through but reflect on, that is what theology is for any believing person."

Again, Julie understands this lived experience as the principle locus for God's self-disclosure in the midst of HIV. *"There is no element of our desire to understand the Divine and communion with the Divine that cannot be brought closer to us through that experience."*

She also emphasised the epistemological privilege of people living with HIV: *"Who are the teachers of theology? Where is the source of our theology? People living with HIV are the people who are teaching others about what it means theologically to make sense of HIV. It is not something that comes from bishops obviously, and yet some people think that's the only place it can come from...[It is people living with HIV who] can help others towards what it means to live as though God exists."*

For her HIV represents more than a set of intellectual theological questions. Her Christian life and her task as a theologian are made more relevant by HIV. It is a matter of personal importance because her faith has been enhanced, and her spirituality enriched through her encounters with HIV. I will return to this below. The pandemic also creates an urgency, requiring theology to be crafted in such a way that theology itself has greater relevance for the wider church and especially for those people who are directly living the big questions of health, healing, loving and dying: *"If you are going to talk about theology it has to, in some way, be Good News for people, not bad, and unfortunately a lot of it has either been bad news or it's been inaccessible; they haven't a clue what it means. That kind of dusty irrelevance, we haven't got that luxury any more, things are really urgent, and we need to shape up and get cracking, talking to people in plain language and not just giving them easy answers...I don't want that kind of theology I want it to be something that speaks profoundly of human experience."* She doesn't *"think we have got very far in the last 30 years. In a sense we [theologians] are only just beginning theologically, to do the deep reflection, we are only just beginning to scratch the surface. I don't think we have got at all, deeply to the bottom of any of the issues yet, I don't think. So, how to do theology in a time of Aids is a big ask."*

Julie made an interesting comparison with the ways in which the feminist movement and intellectual reflection on feminist issues proceeded in stages, the so called 'waves' of feminism. *"I don't know if that parallel goes any further but if there are new waves of*

reality, the reality for example of living with HIV rather than the reality of dying with Aids which was the experience before...So there could be waves of reflection, if not discernible now [that] will become discernible.” She described her theological reflection on HIV as a process of conscientization, similar to the way she became more aware of herself within a feminist context. She also observed that as part of this individual and collective process there is often a need to state the same ideas, challenges and questions repeatedly, until they become accepted.¹⁹⁷ *“Over history we will see more of the same as well as newness and deepness as well, I think. We will just have to be patient.”*

Lastly, if deeper theological reflection is needed within the context of HIV, if we are to move beyond ‘the dusty irrelevance of easy answers’, Julie appealed to the traditional Christian resource of contemplation: *“When we think about Christ living with [HIV], the body of Christ, that really invites you in a theologically rich way into the Passion...what happened in the darkest hours in the final days of Jesus and that’s a very rich and profound theology that I can’t do justice to here.”* She acknowledged that reflecting upon HIV through the lens of the Passion of Christ is not unproblematic. On the one hand, there are possible ways of making sense of a person’s suffering via identification with *“Jesus the innocent victim of the world’s exclusion.”* On the other, *“there’s also that awkwardness that also comes from associating HIV with Jesus as the victim, because that could also be an objectifying or victimising thing, a disempowering thing for people living with HIV...I see a kind of ambivalence there, and yet I also believe that you’ve also got the evidence of the extraordinarily powerful and transformative grace filled moments from what the existence of the virus has done for human encounter. It has opened up extraordinarily profound human experiences that would not have been available to people otherwise. So, we have to live with those layers of ambivalence. And maybe as Christians we should be good at this. Because the whole thing*

¹⁹⁷ This tendency to repetition of the same messages within a ‘movement’, or the repetition of the same message within a given context over time can be evidenced within the theological literature on HIV. For example, in Kurian’s 2016 summary of the WCC involvement in combatting the pandemic over 30 years he feels the need to repeat that understandings of Aids as a punishment from God are types of false theology, and repeat the associated message that the whole church needs to repent of the ways in which Christians have contributed to the suffering that attends HIV. The same repetition of what might be considered basic corrections to bad theology are evident in Leclercq, 2010. This thesis also repeats many of the basic learnings from the encounter with HIV in the light of faith, and I have considered it necessary to do so, despite the fact that many of the points that I make again here, have been made many times before, in different ways by other authors. I will return to the fact of having to repeatedly raise the same fundamental issues related to HIV and Aids in my concluding chapter.

about Christianity is paradox isn't it? In our weakness we are strong, and the victim in fact becomes victor. So, that in a way is what we're invited to enter into by reflecting on that phrase 'the body of Christ has Aids', mantra like, to be drawn into a deep theological and spiritual reflection, as a stepping stone into the deep pool that reflection on this issue takes us into."

Kevin Kelly (1933-2018) was a Roman Catholic priest of the Archdiocese of Liverpool. He had worked as a theological consultant to Cafod. At the start of our interview he referred me to his book *New Directions in Sexual Ethics: Moral Theology and the Challenge of AIDS*, which remains one of the most influential works of theology arising from reflection upon the HIV and Aids pandemic. Much of our conversation reflected the theological arguments he made there. In it he argues that HIV challenges moral theologians, and the Institutional Church, to come up with a more adequate and convincing sexual ethic without which the Church cannot shoulder its responsibility to combat the pandemic in those communities most ravaged by the disease (Kelly, 1998, p.xi). He argues forcefully that the Church must take on board, comprehensively, the challenges to Patriarchy that HIV exposes through the ways in which HIV and Aids thrive on the deep-seated sexual and economic inequality of women. He calls it a 'structural sin' with which he and his fellow male clergy in the Church collude to a lesser or greater extent (p.21). He concludes that as a guiding principle for Christian sexual ethics, the Church must be pro-women before it is pro-marriage (p.63). He also challenges orthodox teaching in regard to gay sexuality and insists that the Gospel must be good news for gay and lesbian people as well as straight people. He reverses the proposition when he writes that "Perhaps the Good News in a 'time of AIDS' is inviting us to fall down and 'worship' gays and lesbians *as the persons they really are in God's eyes!*" (p.95).¹⁹⁸ Here, Kevin echoes the point made elsewhere by John Sherrington, CP, who speaks of how in his pastoral ministry alongside people living with HIV 'his own Christian life has been enhanced by them.'¹⁹⁹

As with all of these interviewees, the point is made, that meeting people living with HIV has often been an occasion of challenge, learning, and personal growth in faith: there has been

¹⁹⁸ The emphasis and parenthesis are Kellys.

¹⁹⁹ *Positive Faith: Why is HIV an Issue for Christians?*

an exchange of Good News in the experience, often expressed as a grace-filled encounter with the Divine. Kevin proposes a sexual ethic that has as a fundamental criteria and starting principle, the dignity of the human person in their own situation and circumstance. Below I will cite Kevin's words regarding the importance of listening to individual stories as methodologically important for theology.

David McLoughlin and I first met in 1996 when he attended a training workshop on HIV for clergy in the Archdiocese of Birmingham, which I co-facilitated. He was then engaged in parish ministry as a Catholic priest, but has since ceased to exercise his priestly ministry formally. At the time of interview David was the Senior Lecturer in Theology at Newman University, Birmingham. Responding to my questions, he also began with the over-arching fact of suffering. *"It links in inevitably with questions about suffering, how can a just God create a world in which people can suffer in such a way and so on, the question of theodicy...but as such, it is not particular to HIV in itself. The other range of issues are more specifically moral-theological, and they have to do with the context within which HIV is passed on."* He recalled how, in the UK where there were helpful Christian responses, this relied on individual Christians rather than anything more systematic or institutionally supported. In general, the attitude both institutionally and at the level of the ordinary parish to people diagnosed in the early decades was characterised by judgment and fear: *"a sort of disgust that was based upon just a moralism really."* In part he ascribes this to the strong association with gay sexuality: *"You weren't dealing with people who were just ill but people who were ill because of their life choices. So it was almost well it's their fault isn't it. Doesn't mean you won't support them, help them, and all the rest of it, but it was still of their choice."* He told me about people that he still knows who are straight and living with HIV, and importantly he shared his experience of accompanying his younger brother who was gay and died from AIDS in the 1990s, to which I return in chapter six.

Much of the focus of our interview was on human sexuality generally and gay sexuality in particular which he identified as unfinished business for the whole Christian Church. David thinks that Roman Catholic teaching on gay sexuality *"lacks integrity"*. He referred to the fact that the Church has known about the existence of gay men throughout history, and amongst the clergy. Even today *"it is no secret"* that there are men in senior Vatican positions *"who are gay, and actively gay. And yet, [the Church] puts out an extreme moral*

teaching about unnatural acts and so on, based on natural law, which is such a crude way of dealing with moral issues.” However, the “fruits of the Spirit” are evident in many gay relationships, so the teaching ‘On Homosexual Persons’²⁰⁰ is “open to serious rational criticism” as is the very particular view of human sexuality more broadly: “The Church has just not attempted to come up with an adequate theology of sex and sexuality for the modern world; post-Freud, post-Marx, post the idea of human development. We work out of some curious model of human sexuality which is almost impossible to understand.”

Lastly, David pointed to some of the consequences of an “inadequate ecclesial view” and his criticism is made in unequivocally strong terms: *“The big scandal for me, at a practical moral-pastoral level has been the inability of the bishops to face up to the use of condoms, especially in Africa. Just staggering, staggering, condemning people effectively to illness and possible death.”* He told me that he knows of several Irish and European missionary bishops who had been asking that this problem be addressed for several years, *“but they are just ignored by the Vatican, and it seems to me this is wicked, it is a wicked thing. There is a willfulness there that I find shaming as a Catholic. I have challenged bishops and people on it, but they just don’t seem to be able to shift and I do not know why. It’s a bit like Patriarchy really, it is self-evident that it is a limiting factor in religious life and yet they can’t seem to shift.”*

Sebastian Moore, OSB (1917-2014) was a Benedictine monk of Downside Abbey. I first met him after he returned from many years teaching in the United States of America. He wrote several books, and in his later years he would produce a daily theological reflection, which could be found scattered throughout the Abbey pews where he had left them to catch the eye of any passing visitor. His principle focus was the *“the elemental desire for life, [and] for God.”* His phrase ‘desire is love trying to happen’, which he described to me as a *“lucky break”* that came to him in conversation with his students, are Sebastian’s most popularly requoted words. To the end of his life Sebastian was thinking, pondering and writing theology.

²⁰⁰ CDF, 1986. See Gramick and Furey, 1988.

He began our interview by raising the over-arching theme of attitudes to the body: *“Disgust with my body. A tendency or impatience with my body, that sort of thing. I would see that as very much aggravated by HIV.”* This led Sebastian to raise issues of sexuality and human sinfulness within the context of one’s desire for God, and how he had struggled most of his life with both self-acceptance, and his ‘acceptability’ just as he is, before God. The Catholic approach to sexuality within which he was formed as a young monk and a priest, he told me, was deeply flawed and pastorally unhelpful: *“The Church took on a solitary approach to sex: Sex as a solitary problem, a heresy of individualism.”*²⁰¹ He laughed as he told me how he used to hear the *“confessions of young courting couples, as though they were seminarians. Asking questions like, ‘did they go too far?’ ...it was treating them as though they were seminarians, they were not, they were boys and girls, in love and out of love.”*

Sebastian told me how he had only recently come to accept himself as a gay man: *“If I take the last thirty years, it is only fairly recently...that I have completely accepted myself as gay. If I go back before that, it was a sort of a muddled catholic consciousness, well I knew I liked boys and men, the chemical fact was there, but my attitude to it.”* He met James Alison, with whom he felt quite uncomfortable to begin with, as though he was entering dangerous uncharted territory: *“Here was a fully-fledged theological voice, saying, ‘no this [Church teaching] is not right, this was wrong, it’s got to be changed’.”* Sebastian’s discomfort is understandable. Beliefs that he had held about himself for most of his life, and about God, and the authority of Church doctrine, were all being challenged. During his time at Boston College he recalls being offended when visiting theologian, Dan Maguire, delivered a lecture and asked *“what is God trying to teach through the existence of Gay and Lesbian people?”*

²⁰¹ Sebastian referred to The Church having *“taken [this approach to sexual relationships] on lock, stock and barrel”*. He did not specify, nor did I ask him to clarify the source from which these attitudes came, as implied in the phrase ‘taken on’. However, he was clear that there are alternative approaches to sexual relationships and love in the Church’s tradition e.g. the writings of Abelard, and the tradition of same sex blessings as argued by Boswell, 1995. When I asked him about the continual linking of sex and sin, Timothy Radcliffe made a similar point, with reference to Charles Taylor (2005) who has argued that this is *“a relatively recent habit”* picked up from the Enlightenment thinkers, and reinforced in the secular age, *“because of the Enlightenment concern with control. And sex became the symbol of the individual loss of control.”* (Radcliffe). The point here is that whilst it may appear to some people that individual sexuality morality has always been a preoccupation for the Church and theologians, the history and development of attitudes to and doctrine on matters of human sexuality is a much more complex and diverse tradition.

And I was shocked by this!" Sebastian admitted that his own internalised homophobia [mis]informed his reactions to the outbreak of Aids to which we will return in chapter seven.

The writing and thought of Eckhart Tolle was a second major influence in recent years, which had a profound effect on Sebastian's thought and writing.²⁰² Sebastian described his 2011 work, 'The Body of Christ: The Shudder of Blissful Truth' as *"doing theology after Tolle."* He was perplexed that no mainstream academic theologian had picked up on the ideas of Tolle. As he said to me, *"This stuff is Gold! A hermeneutic of bliss."* It was Tolle's own 'mystical' experience that first captured Sebastian's attention: *"I read it, and I was there!"* In very brief summary, Tolle describes an experience within which he was overcome by a sense of the impossibility of being divided against himself, which drove him to a point of near despair (Tolle, 2005, pp. 1-3). In the midst of this *"[Tolle realised] 'I cannot get along with myself – why? Are there two of you? Maybe one of them is false.' And it frightened Tolle. And the voice said to him 'resist nothing'."* Sebastian related to it deeply, because Tolle gave words to a similar experience he had as a young man. In 1944, like all the monks in formation, Sebastian spent an hour each day *"in this thing called mental prayer."* He continued: *"It was a torture of being conscious of the presence of God. I messed up my brain, forcing, forcing, forcing; and then one day in early October, something said, 'be honest'. I said, this is nonsense, I don't believe it, it's rubbish, I don't believe it. And I was caught. I still don't know what happened. But I heard myself saying, 'I will give you anything you want, I'm in love!' I walked up and down trying to take it in, and I came back. I knelt down again and felt all the pretensions in my life coming through layer upon layer, and I said yes Lord, [take] that one too, the lot!"* Sebastian described an encounter with the Holy Spirit, and crucially, the liberation from those thoughts and 'disciplines', in this case a taught method of monastic prayer, which he experienced as imposing a type of spiritual straight-jacket; a set of demands that he could not meet despite all his efforts. In this story he described letting go of a set of conditions which he had thought necessary for encountering the Divine. He faced the painful truth of his own experience, and in that moment he 'allowed' God to meet him as he is, rather than as Sebastian thought he should be. From this moment of absolute honesty with himself, Sebastian made room for God to capture his heart with love.

²⁰² See Tolle, 2005.

Sebastian tugged away at a thread in Tolle's writing, which Tolle calls 'the pain body'. Sebastian gave it his own term: *"I call it 'anti-bliss'; it expects pain, it says pain is deserved, pain is the way it should be; [Tolle] talks about an inherited pessimism, a proclivity towards 'no'; instinctively feeling negative about the body, and God knows, that is our Christian heritage, with the body as a sexual danger."* The phrase captures more than a "body-negative" attitude; it encapsulates a world view with anthropological and theological implications. The 'voice' of anti-bliss insists that *"pain is appropriate, we ought to have pain. You're not supposed to be happy."* The human condition is one of misery, which is deserved because human beings are fundamentally bad. *"I'm sure you have a tradition of Irish melancholy. What Wordsworth calls 'the sad tale of our humanity, sin.' Tolle calls that 'the pain body', I call it anti bliss. It was a revelation to me. When I read that man talking about an inherent pessimism, sadness, a preference for the sad, the safer, I heard me... We feel bad about feeling good. Why? That Tolle says is the pain body."* He talked about how a misunderstanding of the doctrine of original sin adds to this conditioning: *"Eckhart would say original sin is the same as 'conditioned mind.'"* Sebastian agreed with the educational psychologist Alice Miller who,²⁰³ despite the protestations of many theologians that she misunderstood the doctrine, wrote about a 'poisonous pedagogy' based in part on the Christian idea of original sin. *"She said 'no, in practice this is the doctrine of original sin, and it is poisonous, it's toxic, and it makes children feel low and bad'. A prophetic woman."*

Sebastian's position included a rejection of Augustine's notion that original sin is transmitted during sexual intercourse: *"It can't be true. Abelard saw through that...He knew that the official doctrine...was bad stuff, because Abelard was a lover. This idea [that] sexual intercourse communicates something like a spiritual V.D. is horrific."* Sebastian viewed original sin not as *"something we're born with, it's something we got into."* To return to the 'voice' of Tolle's pain-body, Sebastian warned against confusing original sin with concupiscence or desire. *"Don't confuse original sin with concupiscence or desire, that's Luther. We don't want any of that. Don't connect original sin with concupiscence or desire."*

²⁰³ Alice Miller (1923-2010) was author of many books on childhood trauma as the root of personal and societal problems.

*Original sin is something else. It's a lack of something." Original sin "is the most massively misinterpreted doctrine we have I think. Bad theology."*²⁰⁴

He spent a lifetime, he told me, un-doing this internalised toxic theology that made him feel bad about himself and suspicious of his own desires. Framing the human condition as a kind of deserved punishment, and viewing creation as inevitably bad and dangerous stands in opposition to the promise of Christ who 'comes to bring life in all its fullness'.²⁰⁵ It shapes an attitude that goes beyond just a loathing or suspicion of one's body, and causes us to resist all that life brings. *"It is all very well saying 'bad theology' but... mummys and daddys hand it on, but it is bad theology. And it consists in 'pain is appropriate.' We feel bad about feeling good, we shouldn't feel good, and a misuse of theology says 'and that's original sin'. It's not."* To return to the 'voice' of anti-bliss: *"I made a distinction ages ago, between the doctrine and the voice. The voice of original sin says, for instance, 'there will always be war, and that's the way it is' that is original sin speaking, it's not the doctrine of original sin. The doctrine of original sin should be saying, 'look, watch out for that voice, because it doesn't come from a good place'."*

Lastly, Sebastian reflected upon what can be said now about Christian faith in the midst of HIV and Aids: *"It is not saying much saying 'it isn't a punishment.' More needs to be said. And to say it is a challenge is tired. I think most importantly it has been a call to love one another. And to show love, in incredible ways. It has evoked a heroism in gay friends of mine which is beyond this world. An evocation to love, to heroism."* In the next chapter I will say something more about the thought of Tolle as important for one of my later interviewees, Joseph.

Timothy Radcliffe OP was the first English member of the Order of Preachers, known as the Dominicans, to be elected to lead this global religious order from 1992 to 2001, since the foundation of the order in 1216. He is a Roman Catholic priest, internationally sought after

²⁰⁴ The Catechism of the Catholic Church (CCC) para. 405 calls original sin 'an inclination to evil that is called concupiscence'. On a different occasion Sebastian told me that when the new 1992 version of the CCC was published he wrote to then Cardinal Joseph Ratzinger, head of the CDF, to protest the entry relating to the doctrine of original sin. Sebastian felt strongly that an opportunity had been missed to restate the doctrine in more theologically sophisticated and relevant ways. He laughed when he told me that he received a short reply from Ratzinger thanking him and informing Sebastian that his letter "will receive the attention it deserves."

²⁰⁵ Jn. 10:10

preacher, and author of several books. He was the 2007 winner of The Michael Ramsey Prize for theological writing, for his book 'What Is the Point of Being a Christian?' As a Cafod trustee and in his role as Master of the Order he saw how HIV and Aids affected people and communities across the world. He has also contributed to the 'Positive Faith' internet resource since this interview took place. Much of our interview was focussed on past experience, with insights for theology and pastoral ministry today.

As with Sebastian Moore, the first issue that HIV brought to prominence for Timothy is a reminder that *"We are bodily. All the great moments of our redemption concern our bodies. Our bodies are good, our sexuality is good, it is a gift. That God became flesh and blood with us. That we receive the sacrament of His body, and we look forward to the resurrection of the body. And so that means that any illness that touches the body is important to us as Christians. The first Christians astonished the Romans because they cared for the sick, even people they didn't know."* Related to this, Timothy has appreciated more fully, the importance of human touch. *"I began to see how important that was in the ministry of Jesus. Where He was at ease in his body, and He was at ease with other people's bodies. Whether it was the woman who came to wash His feet, or Jesus washing the disciples' feet."* Aquinas spoke about touch as the most human sense, because *"it is reciprocal, good touch. You can see but not be seen; hear but not be heard. But if you touch you are touched. Touch is inherently mutual."* I will come back to the importance of this sense of touch in chapter eight.²⁰⁶ In view of the sexual abuse and physical violence that has been inflicted on so many people I do not think it is responsible to speak or write about touch theologically, without acknowledging abusive touch. Timothy spoke about how *"the rapacious touch"* and issues of abuse in the Church have made us fearful, but insisted that we have to find a way to recover the capacity for touch that is affirming, respectful, tender and healing. He recalled how those first experiences of visiting people at The Lighthouse²⁰⁷ or in HIV wards

²⁰⁶ Timothy still remembers the experience of Michael Lopez OP who spoke of holding the body of Christ at the Spode Conference which I considered in the opening chapter of this study.

²⁰⁷ See chapter one. The Lighthouse can be said to have contributed to advances in best practice within the health sector generally. It provided innovative approaches to the support and care of people with (then) terminal illnesses which have informed many approaches to community care today; and as a model for end of life care and treatment it advanced best practice within the hospice movement. See Spence, 1996.

“really brought home what it means to believe in the Incarnation; which is God becoming flesh, God becoming vulnerable and God becoming touchable.”

Second, Timothy thinks *“that HIV has awakened our sensibilities as a community to the ways in which people can be marginalized. Thanks be to God that’s no longer the case, and that is a great victory.”* He contrasted the HIV stigma of the eighties with all the attendant fears and ignorance, which resulted in people with HIV being ostracised, even in medical settings, with the situation today. *“[I] realized that the Church’s reaction to HIV was a test of our discipleship to Jesus, who was never afraid to be in contact with the sick. When people are pushed to the edge, that’s where Christ is, and so our reaction, as a Church was indicative of our fidelity to Jesus.”* As prior during 1985, he asked his community to consider offering respite to people living with HIV, their families and partners. When his suggestion was accepted without hesitation or qualification, he was deeply moved: *“They were not interested if someone was HIV positive, if they were here as a guest, they were here as a guest. [Actions like this] were part of the demythologizing.”* Timothy remembered other compassionate responses to members of the Order that were living with HIV during the first decade of Aids. There was a brother in the San Francisco province who suffered with Aids. The Provincial, who was also a doctor, moved him into the provincial house *“and washed him every day.”* In the Canadian province another brother was admitted to solemn profession and later ordained whilst living with Aids, with the full consent of his religious superiors and the local bishop. *“The province saw [living with Aids] as part of his priesthood, and that was very powerful.”* Timothy spoke with him the day before he died. *“It was very moving that his own community saw his life and ultimately his death, as a sort of preaching.”*

In those first years, Timothy came to understand that *“faced with someone who is HIV positive, the question of how they became infected is irrelevant. This person is my brother or sister in Christ, and that alone matters.”* Through the Spode House conference; coping with the reality of HIV and Aids in the life of their religious community; and through pastoral ministry, Timothy realized that *“there were communities of people, especially the gay community, which had much to teach the Church...their courage and charity was a lesson for the Church. But the Church was unsure of how to relate to such communities, especially*

given it's teaching on sexuality. I believe that we cannot answer those questions without friendship, giving and receiving hospitality."

Necessarily giving and receiving hospitality, and beyond that friendship, depend upon an initial stance of openness to others, which raises a further question: how willing are we to engage in any encounter with others who may disturb us or challenge our views, opinions or doctrines? This question, it seems to me is a fundamental challenge for any Christian, and applies not only to people living with HIV, but to any person who is on the margins of the social group within which we ourselves exist and feel already 'at home'. If, after the manner of Jesus we aspire to be alongside those who are marginalized and vilified by wider society, how willing are we to enter situations where we meet others who make us feel awkward and unsure? *"I would hope that the Church would be more courageous in embracing, in every sense, people with HIV. In our society we are so nervous of people getting the wrong message that we often lack the guts to take the risk. There is no sharing of the gospel without the risk of being misunderstood."* In common parlance, are we willing, are we able, to risk venturing beyond our 'comfort zone(s)'? This challenge also had implications for me as I continued my research, to which I will return below.

Lastly, Timothy agreed with Kevin Kelly and James Alison in situating sin always within the context of forgiveness. He expanded the point: *"It is often said that the trouble with our society is that it has no sense of sin. I think it is the other way around, I think we are burdened with an enormous sense of sin. And you can't talk about sin until you first talk about forgiveness. I think that when people know they are forgiven, and as Herbert McCabe²⁰⁸ said, we are forgiven from the beginning of creation, then you can look at responsibility because you know you are forgiven. I think we can't easily talk about sin because people suffer under their own dreadful burdensome culpability."* The evidence of this burden will be evident in Part II. *"You see there's the idealism that says with the Grace of God and through all our mistakes and with lots of forgiveness we are on our way to a plenitude of love beyond our imagining. That's very different from the sort of moralism which says 'and we've all got to be extremely good, and your failures are shameful'; I think that's what we live under and why I never talk about sin until a long way into the*

²⁰⁸ Herbert McCabe OP (1926-2001) was a prominent Catholic theologian and philosopher

conversation, where people know that they are loved unconditionally.” Below I will expand upon how Timothy’s learning from the context of HIV and Aids has contributed to his understanding of the task of doing theology.

4.4 Fundamental suffering.

The questions posed by the fact of suffering in the midst of HIV was mentioned by all my interviewees as a major challenge for theology. It is that most fundamental of questions: how a good, all loving, and all-mighty God can allow suffering, especially ‘innocent’ suffering. As Christina Beardsley framed the problem:

“Why do we have this virus at all? What does this tell us about God, the world we are living in and being human?” (Beardsley)

Julie Clague identified theodicy as one of the major theological problems of the 20th century. She remarked that theologians have been challenged by the problem of evil, especially in the aftermath of the Shoah. Given that HIV and Aids has had an impact of global proportions, she expressed some surprise that theodicy has not received more attention in response to the HIV and Aids pandemic. She referred to a *“curious gap”* in academic theology with concerning implications:

“It is surprising that you don’t hear more of that kind of question, and that’s a bit worrying really. It’s as if to imply maybe, that in some way God intends suffering...the question is not ‘how can God permit this’ but in some way, the question or victimising finger-pointing that goes on is towards the people who are affected or living with, and they’re the ones that in some way are blamed for HIV, and the big finger doesn’t point to God, and that strikes me as interesting, at least not very often do you hear that theodicy question.” (Clague)

Julie’s observation of a ‘theodicy gap’ cannot refer to a lack of theological writing on the dimensions of human suffering that attends HIV, of which she is aware.²⁰⁹ I interpret her

²⁰⁹ She is correct that since HIV and Aids first demanded theological attention, there have been very few attempts to address theodicy as an abstract philosophical-theological category from within the context of the pandemic. Of the few examples that I have found see: Allen 1995; Conradie 2005; Orobator 2010. That is not to say that the question has not arisen, by implication, if not more directly. As outlined in my introductory chapter, the theological controversy which dominated public debate when Aids first appeared arose because of those explanations which ‘defended’ or sought to justify God in the face of suffering, most obviously by interpreting HIV and Aids as divine punishment, and were thus related at least tangentially to the problem of theodicy. The philosophical question of theodicy is not the focus of this thesis. I have drawn some lessons from

remarks as revealing a frustration with the theological, pastoral and ecclesiological responses thus far, and her impatience that the churches remain somewhat 'stuck'.²¹⁰ Another way to express this is to say that we are yet to get beyond questions of blame and culpability, and this has an inhibiting effect both on our pastoral responses to people living with HIV, and our mission-capacity across all denominations, to witness to the Gospel as good news, especially for those communities and individuals most affected by HIV (Orobator, 2005, p.18).

Institutional responses and the culture and practice at the level of the local church, remain preoccupied with issues relating to the question of personal sin. In spite of theologians' efforts to counter interpretations of HIV as a form of divine punishment, in writing and in practice, in subtle and not so subtle ways, theodicies which serve to 'protect' God by locating blame with individuals, whether consciously or not, continue to exert an influence.

Agbonkhanmeghe Orobator (2010, p.75) makes the same point differently when he writes that "the debate about the transmission and prevention of HIV, and about the care of people living with AIDS, is strewn with dogmatic declarations of the righteousness of God and the moral liability of people living with AIDS."

Julie provided an example of how this habitual 'tendency' to ascribe moral liability qualifies church responses which then become obstacles to collaboration with secular public health agencies. In November 2011, she was a consultant to the EAA and WCC 'closed-door' workshop discussions on 'Theology, Human Rights and the HIV Response'. Religious leaders, representatives from UNAIDS and people living with HIV met in Geneva to promote debate and research into the often sensitive human rights issues relating to HIV. The overall aim

this and other aspects of the interviews which raised more abstract philosophical and theological questions, to which I will return in this chapter. However, what matters here is the ambiguity of Christian attitudes towards people living with HIV which Julie is naming, and the tendency to blame that arises, which point towards an ongoing reality in the churches, and contextualises this research.

²¹⁰ Julie's interview with me was conducted in two sessions. The first was conducted at her office in Glasgow University. Due to time constraints on that day, and her wish to continue the interview, we scheduled a follow up interview by telephone. In the course of the second session she retracted an initial opinion that the responses to HIV from within the English and Welsh Catholic Church, mostly through the work of Cafod, were good, and something of which we could be 'proud', especially in comparison to Catholic responses in other parts of the world. In the second session, she qualified her positive remarks about Cafod's efforts, and explicitly described the Catholic Church response in the UK as quite inadequate; too often tentative and constrained by the hierarchical structure and culture of clericalism within the Catholic Church, "in which we are all implicated."

was to overcome ideological barriers and facilitate dialogue between faith communities and non-religious agencies (Paterson and Long, 2016, p. xxiii). At an early stage of these discussions, some of the Christian leaders present began to qualify any possible responses that they or the churches they represented, might be involved in:

“People saying things, for example, like, ‘we can’t really accept the kinds of lives people living with HIV live, within our community because...’, and then lots of moral lists of naughty things that people living with HIV are supposed to have done... And that group of people were very divided on that kind of question.” (Clague)

This example shows how difficult it can be for churches to work collaboratively with public health agencies because of theologically based judgments, especially those relating to areas of individual morality. Of more significance, Julie noted that HIV holds a *“..mirror up to the Church, and what we see is not a very pretty picture”*. Not only are tensions between secular public health agencies and the churches revealed, but painful divisions between Christians are also exposed by HIV:

“We are a very plural Church, and we haven’t a clue what to do about that, except thinking that we are right, and that lot over there that have another view are wrong. That’s how I am. What am I meant to do with that? That’s a real challenge for the Church, community...it’s not an elephant in the room, it’s a very visible presence...” (Clague)

Very often Christian responses are conditional responses. This evidences one of the ways in which the churches remain ‘stuck’:

“When the epidemic first exploded, its message was clear for many people: they believed that God had finally visited a plague of biblical proportions upon God’s wayward people. Orthodox and fundamentalist ethics lined up the usual suspects, namely commercial sex workers, sexually promiscuous people, intravenous drug users and homosexuals, in the firing line of divine retribution.” (Orobator, 2010, p.75).

I take Julie’s worry as indicative of how the churches, in this case Church leaders, remain in that place where the association made between HIV and sexual immorality continues to dominate as a primary concern that informs, or misinforms, our Christian responses.

The objection may be raised that I am confusing moral theology and theodicy. Certainly, there is an academic distinction to be made, but the two are related in several of these

interviews and the work of others (McDonagh, 2000, pp. 317-318). Julie's linking of these areas of theology as worrying, reminded me that what we believe about divine justice and mercy determines the quality of welcome we are willing to extend to those who are infected with HIV. As we will read in Part II the links between one's own actions and moral standing before God, and the questions of theodicy do arise for several of my later subjects after diagnosis.

At the time, I continued to wrestle with the implications of this ecclesial reality that Julie and others identified. If the capacity of Christians to respond to the suffering that arises within the context of HIV remains constrained due to unresolved theological tensions; if what we believe about God and in turn what it means to be the body of Christ, generates stigma, prejudice and exclusion in practice, are their particular doctrinal positions that should be abandoned? Even more challenging, might the many detractors and critics who accuse the Church of being a part of the problem rather than contributing to solutions be right? Does Christian theology itself cause much of the suffering that attends HIV, and if so, are there fundamental aspects of 'orthodox' theology in need of radical revision?

4.5 Situating fundamental suffering in research

It is not surprising that questions related to the meaning of suffering came up when the reality of HIV and Aids is so obviously a situation of human suffering, which invariably calls God into question. Each interview was concerned with this question, and as the overarching theological challenge it was in my mind as I began my research. The questions that I had asked and my own determination to be open to whatever might arise in the course of these preliminary interviews, allowed us the scope to consider some fundamental doctrines, and touch upon this big existential question of suffering.

However, although the fact of suffering emerged as fundamental for this study, the question of suffering was not pursued in the abstract in the course of these interviews. From further reflection I think there are three reasons why not, which also had a bearing on the direction that my research took:

First, there is no satisfactory theological answer to the fundamental question of why God allows innocent suffering (Schillebeeckx, 1970, 1972, 1977). The existential fact of suffering and evil alongside the existence of an all-powerful and all-loving God is a paradox, which

cannot be rationalised away (Wittenberg, 2007, p.163). If all the theologians before me have not provided a satisfactory answer to the philosophical ‘problem of evil’, it is unlikely that I would hit upon a solution (Mc Brien, 1994, pp. 345-346).

Second, each of the theologians emphasised the importance of starting from human experience if one is to make faith-sense of HIV in the body of Christ. I will say more about this balance between experience and more abstract intellectual thought as spoken about in the course of these interviews later, for now it is enough to make the point that within the stated aims of this research pulling on intellectual threads abstractly, was not likely to be particularly useful.²¹¹

Lastly, as I discuss below, although we did not necessarily share the same appreciation of the extent of suffering within a Western context, that suffering is a part of the phenomenon of HIV was taken for granted by us. The research question was posed in very practical terms. My intention was to find faith-meaning in this context, rather than solve the philosophical and theological questions raised about the very nature of God and God’s way of relating to humanity, that theodicy raises.

Who God is and why God allows suffering, must be understood as a key theological ever-present question, raised by HIV. In Part II these questions will be raised again many times in the words of my second group of interviewees. In terms of personal faith, it is the most disturbing of questions. In terms of the claims Christian theology makes about God, and consequently claims that the Church makes about itself, it is fundamentally disruptive.

This most paradoxical of challenges to Christian faith arises in many other situations, but making faith sense of suffering “..takes on a particular shape in this context” (Kelly), and requires that we remain close to the actual experience of suffering undergone in communities and by individuals most directly affected by HIV. Theological inquiry that seeks to find ‘God in all this’ can only be pursued with both feet on the ground of actual suffering, within the context of this theologically ambiguous landscape.

²¹¹ Kevin Kelly was especially keen to avoid abstract theological language. We had been discussing the recently published book by Jack Mahoney, 2011, *Christianity In Evolution: An Exploration*. Kevin asked me if I had read Chapter two in which Mahoney writes about God as being ‘altruistic’. “I wrote to him, and said, I don’t like that word, it sounds like an abstract doctrine. To me God is a living furnace of bubbling over love. Nothing abstract.”

4.6 Learning from the encouragement of others

As I argued in the previous chapter reflexivity is methodologically important. Here I want to make some points that were significant for my learning and influenced the way in which research proceeded.

Above I explained that I had met most of my interviewees before and how this allowed me access to them that might not otherwise have been available. Our pre-existing relationships made a difference to the quality of the conversations. However, following these interviews, I was struck by the fact that Kevin Kelly, Julie Clague and David McLoughlin each referred explicitly to our previous meetings, sometimes recalling in detail a contribution that I had made at the time.²¹² In terms of an approach to theological research I consider their remembering significant, in three related ways:

First, they reminded me of experiences that we shared but I had almost forgotten, and the questions, theological themes, and ideas that we had struggled with at that time. I found it personally encouraging that they recalled these encounters as important moments in their own process of theological reflection. They reminded me that we were engaged in a theological conversation that had started much earlier, and one to which I had already contributed meaningfully. I realised that intellectually I had been skipping over all this, as it were. My inattention to the past, because I was involved, risked under-valuing the significance of these historically important encounters. In part this realisation motivated me to include historical detail in this study, particularly in the introduction and chapter two, and in several footnotes.

Second, that these theologians could quote the detail of prior experience, and sometimes what I myself had said, validated the sharing of personal experience as a source of theological insight.²¹³ Their memory of my contribution as significant reinforced my commitment to place the lived experience of Christians diagnosed with HIV at the heart of this study and the process of research. I was strengthened in my conviction that to do so would be theologically fruitful. If my academically uneducated voice from almost twenty

²¹² See footnote 189 and Section 4.2

²¹³ My contribution at many of the events to which I refer took the form of sharing and reflection upon HIV as a personal journey in faith.

years earlier is remembered by accomplished theologians, then it follows that the muted voices and hidden experience of Christians living with HIV today are a potentially rich theological source.

Third, each of them conveyed to me their understanding that whatever learning stayed with them from prior theological reflection upon HIV, this research was worthwhile and potentially fruitful because of that sense of continuing a shared journey in faith, one started often in dramatic circumstances, in response to a crisis,²¹⁴ but one that is far from over. I was encouraged that each of them felt that there was more to be understood. That, as a sign of the times, within the phenomenon of HIV and Aids, God has more to reveal. Julie put in well when she thought of HIV as a 'pandora's box':²¹⁵

"We are not going to tidy up this messy world of theology, let alone the messy world of things like human relationships, or human sexual relationships, or human loving, living, and dying. It's all a messy business, and it's all unfinished actually."

²¹⁴ This memory of shared experience at a time of crisis refers not only to the 'war years' of HIV in the UK, nor just to the emerging reality of HIV as a global pandemic which threatened to destabilise whole nations, but also to the sense of being engaged in something that was intellectually and personally dangerous. For example, the 1994 Dublin symposium weekend was held with a high degree of secrecy. I recall being instructed not to tell anyone about the purpose of the symposium, or our location. Controversies over the perceived official Roman Catholic and other Christian responses to HIV, were frequently highlighted in the national media in Great Britain and Ireland. The organising group were aware that during the symposium Maura O'Donoghue, a Medical Missionary of Mary religious sister and qualified medical doctor, who coordinated Cafod's responses from 1987-1997, would share her findings on issues relating to the sexual abuse of women religious by priests in several countries. During the weekend she summarised her findings which later that year, were submitted to the Vatican as a report. She recounted how professed religious women were pressured into sex by priests who would justify themselves on the basis of the increased risks of having sex with other (non-vowed) women given the prevalence of Aids in society. See:

https://natcath.org/NCR_Online/documents/UrgentConcernsO'DONOHUE.htm [Accessed feb. 2019].

Ann Smith recalls that many of the lay academic theologians, the majority of whom were women, were concerned that their involvement may cause difficulties in their academic institutions or jeopardise their employment prospects. For these reasons, the organisers were concerned to ensure that the Press were not aware of the gathering, lest their interest and attention distract us from our task, or stoke controversy within society and the Church. In short, addressing the issues raised by HIV and Aids theologically was potentially controversial, and for some personally risky. (Detail verified in email correspondence at time of writing between author and: Ann Smith, Professor Linda Hogan, former Cafod Director Julian Filochowski, former CI advisor on HIV Msgr. Robert Vitillo, and Martin Pendergast, all of whom attended the symposium).

²¹⁵ Previously I had been exploring what is meant by the phrase reading the 'signs of the times.' I had thought that this theological method might provide a framework, perhaps even the principle theological category, for my thesis. As part of my research I read Leech 2003. On the last page of his book he refers to HIV having opened a 'pandora's box of unfinished business'. It is the only mention of HIV in the book, but it stayed with me, and I used it as one of the questions posed in these interviews. I asked, what did this phrase mean to my interviewees?

“The church has a lot more thinking to do about sex...and a lot more thinking to do about gender, and, where do I stop... and these things are really only things that we began to theologise about properly, in the last 50 years. So this is new, in the history of the Church, ...unfinished in all sorts of ways. [Pandora’s box] is a very rich metaphor I think...” (Clague)

4.7 Balancing listening and ‘sounding out’ and the question of sin

I opened each interview with the qualifying statement that our time together was not intended to be spent in any kind of debate; my aim was to listen to what they had to say. Debate was avoided, but the interviews took a more conversational turn than I had anticipated. This turned out to be beneficial for my own learning for reasons that will become clear. As the interview schedule progressed, when appropriate, I was able to bring the reflections of a previous interviewee into the current interview so that different perspectives were brought into conversation with each other. I restricted my own contributions to follow-up or clarifying questions. I allowed myself to share a ‘theological thread’ that I was pulling at, and sometimes I referred to challenging questions that had been posed to me in other situations, such as presenting a short paper in an academic context.²¹⁶

For example, I had been wrestling with how I should approach the question of sin in relation to HIV. Sharing this with Kevin Kelly and Christina Beardsley was instructive both in terms of the topic and in relation to the craft of academic presentation. I had given a short paper at the 2011 Conference of the British and Irish Association of Practical Theology (BIAPT). In that presentation I argued that talk of sin is neither helpful nor the appropriate starting point as a pastoral response to a person living with HIV. At the close of my presentation a minister in the group asked me the following question: ‘If we are not to talk about sin, how then can we raise the harmful consequences of certain behaviours with people?’ I was unable to answer him adequately at the time, and that bothered me.

Christina recalled an event in her life when, at a meal with friends she had made a judgemental statement about how HIV might be avoided if only people would commit to monogamous stable relationships. What she hadn’t realised at the time was that one young

²¹⁶ For example, issues of inclusion and welcome in the church and the challenge to the validity of my arguments that were put to me at Nottingham University and are described in chapter two.

man at the table had been diagnosed with HIV. She remembers that a “*sort of silence*” filled the room. She felt very uncomfortable in that moment. *“It was quite shocking, that I am doing all this lovely pastoral work and yet could still come out with something like that, and in a way that really wasn’t helpful, because I don’t know what he felt about that being said.”* (Beardsley)

Sometime later, the man’s mother wrote to Christina to tell her that he had died.

“I went then to see her, almost as an act of reparation. Because I thought, it might be true that it is good to be faithful in relationships, but, it only takes one encounter for this to happen, and who the hell are you to be saying things like that to anybody. It was quite shocking, that I am doing all this lovely pastoral work and yet could still come out with something like that.” (Beardsley)

She remembered that at the time she had been addressing personal issues to do with *“...knowing myself loved in my sexuality and not that God blesses you because you are in a faithful relationship, but actually your sexuality is something that’s part of God. You are loved in that...I had sort of made that breakthrough so that really does jar. Obviously I hadn’t assimilated it, the learning that I had come to about being loved in my sexuality and not in my fidelity if you like. Does that make sense?”*

“What I said should have had nothing to do with outcomes. All I needed to say was that faithful relationships are important to me.” (Beardsley)

She considered the possibility that she had been acting under some weight of expectation due to her priesthood: *“Maybe [it was] partly to do with role and what the Institution expects of you. It could be. It wasn’t helpful in that context, and I don’t know why I said it. For me it struck a really wrong note, and something that I must avoid and never do anything like that again.”* (Beardsley)

Later she expressed surprise that she remembered this (and two other examples) from her earlier pastoral ministry. *“Interestingly I haven’t got anything about these three episodes in the notes [I made] in preparation for this interview, but I am very glad to have spoken about them.”* (Beardsley)

Through sharing this experience Christina reminded me that what is asked in regard to HIV often says more about the person posing the question than about those living with HIV. The

ways in which one speaks about HIV is often an attempt to make sense of experience in ways that we find reassuring: *"Maybe, with all these sort of statements, you are talking to yourself aren't you."* (Beardsley)

Kevin Kelly's response to the same question was different:

"Why start talking about the consequences? Why not start talking about the roots to begin with, of certain behaviours. Why people are as they are. That's where, something like original sin can come in, but also the fact that we are all in it together, we are all affected, we all have a shadow side, and so we are all affected and that's simply part of who we are. So again, speaking from the third world, you get to poverty, all those sort of things. Why are people patriarchal? That's a kind of sickness, an evil in the world really, that has to be healed. So, that's why I would not put sin in an isolated context, [rather] broaden the word sin out to mean..." (Kelly)

Me: *"..part of the whole human condition.."*

"Yes" (Kelly)

Me: *"..and our responsibility for creating situations which are unjust."*

"Yes" (Kelly)

I told Kevin that James Alison had said to me that sin should only ever be spoken of within the context of reconciliation.²¹⁷

"I would have said something like that; in a way sin is a positive word in Christianity, because it doesn't exist on its own, it only exists linked to forgiveness and reconciliation." (Kelly)

The theological topic of reconciliation would require a treatment that is beyond the scope of this thesis, however, I think it important to notice that both Kevin and Christina confirmed what James Alison and Timothy Radcliffe understood - that sin and reconciliation belong together. Christina's story demonstrates the reflexivity which allows for repentance at a personal level for her failure to act in more loving ways; Kevin's responses point to the need for a type of communal repentance which leads to action for justice. In both stories, the more meaningful awareness of sin, and therefore an understanding of one's moral

²¹⁷ See also Alison 1998.

response, comes via reflection upon one's own Christian responsibility, and takes precedence over consideration of the moral culpability of an individual person living with HIV.

Because of her background within the Pentecostal tradition, Ijeiy Ajibade was particularly sensitive to how a focus on individual sin can be an 'easy' option. Not only is it not pastorally helpful, but it avoids more uncomfortable challenges:

"In the Pentecostal tradition we can stand there and preach all manner of things about how wrong that [individual sin] is, but where would that message go? It has no meaning to someone who is struggling...The Gospel becomes even more important in [these] circumstances...but in those circumstances preaching the Gospel will mean more than preaching from a pulpit. It requires coming alongside people, without condemning. And that is a lot harder to do, is a heavier weight...than just standing at the pulpit, and is not easy".

"Pointing the finger at individual sin is relatively easy and does not require sacrifice from us. It is simple to do." (Ajibade)

She also emphasized how it is by accompanying people living with HIV that the eyes of faith are opened to structural sin, which then demands a response from us:

*"Coming alongside people and actually being involved in their lives can open our eyes to the multiple ways in which they are restricted constrained oppressed and denied dignity. The many ways in which their choices are limited – or no choices at all."*²¹⁸ (Ajibade)

That HIV is often spoken about generally in society and in church in ways which are reassuring and self-protecting, will be explored in more depth in chapter six. I will also revisit the topic of sin as a kind of personal preoccupation, and the structural and social manifestations of sin in relation to HIV.

In regard to my inability to answer the question posed to me at the BIAPT conference, I could have used the opportunity for learning that the man's question provided in the group if I had posed Kevin Kelly's first question to him in reply, or asked him why this particular question mattered to him. These and other conversations alerted me to the importance of thinking through what objections, arguments or questions might be raised in response to an

²¹⁸ See also Mulligan 2011.

article or a presentation. Any theologian is allowed not to have all the answers, but not to have considered the questions as part of the process of theological reflection, especially ones that might be thought of as obvious once asked, betrays inexperience and naiveté.

In these ways I used my interviewees as a 'sounding board' with whom I could share ideas and thoughts that were occupying my mind at this stage of research. I was able to raise theological questions with them, and as importantly share experiences relating to the theologian's task of communicating in such a way that spaces are opened with others within which reflection can take place upon thorny issues that are difficult to address.

4.8 Theological humility and learning from gut feeling

It is also important to note that most of these interviewees recognised that their formative experience with HIV had taken place in the past. Each of them recalled how they had first been challenged and affected in different ways by their encounters with HIV during the 1980s or 1990s. This is not to say that they are not open to new learning or encounter, but reveals an honesty about their own proximity to the situation of living with HIV today, especially within a UK context, and a degree of 'academic humility' in addressing the issues raised by my current research question.²¹⁹ James Alison's response to the opening question asking what the key theological challenges of HIV are, illustrates my point:

"I could have answered that question for you 25 years ago, but now, I am really not up to speed. 25yrs ago it was about accompanying people who were dying very fast." (Alison)

Several people spoke about their continuing friendship with people living with HIV, as illustrative of how much has changed because of the fact of more effective treatment and in regard to changing social attitudes. Within the context of these personal relationships they

²¹⁹ For example, Timothy Radcliffe, Kevin Kelly, and Julie Clague qualified their learning as coming out of an International Development context and experiences in Africa and other 'third-world' settings. However, this humility in regard to their own sensitivity to or awareness of issues of HIV in a UK context should be qualified by me. For example, Kevin Kelly stated that he continued to be involved with Sahir House, a Liverpool HIV support agency. He supported their work financially, and always attended their World AIDS Day events. He was also responsible for encouraging Cate, who is also interviewed in this thesis, to attend a Positive Catholics Retreat Weekend. Christina Beardsley spoke about past experience but as the senior Chaplain for a London hospital with a dedicated HIV ward, she had ongoing involvement in this form of HIV related ministry. Similarly, Ijei Ajibade speaking about her friends living with HIV today specifically referred to the fact of their ongoing suffering when she stated: *"People are still living with loss. There is real pain in there."* Whilst conscious of gaps in their own awareness and experience, these interviewees were often more actually involved than their humility suggests.

perceived HIV as no longer the dominant factor in their friend's lives; no longer at the centre of shared conversation as it once was. I found the implication that things are very much better now, problematic. I was not quite sure why this quite legitimate framing of the story of HIV and Aids in the context of their own journeys and relationships disturbed me, but I felt a gut reaction of protest at the time. It is factually true that an HIV diagnosis today is not the death sentence that it once was. With increased knowledge and education ignorance about how HIV is transmitted has diminished, and people with HIV are not treated as dangerous, even in hospital settings, as they once were. In the UK at least, stigma has decreased. So why did I feel such a strong visceral response?

As the interviews continued, I found myself tentatively challenging these repeated narratives of progress achieved. For example, during the interview with Timothy Radcliffe I asked whether it would surprise him to know of a woman who had told me that she had decided to end a friendship with a family here in the UK, because each time she visited they would produce a set of crockery and cutlery reserved for her use. I had not prepared this question before-hand, it came out in conversation naturally because of a recent meeting I had had with the woman. It is a small, perhaps trivial example. Having a special cup reserved for this woman's use betrays ignorance on the part of the family, but does not equate with the exclusion of children living with HIV from school, or that people diagnosed with HIV have been attacked, even killed, when their status has been known. Nevertheless, in my own way, gently and respectfully I was seeking to disrupt these narratives of progress that I heard consistently from each one of my interviewees.²²⁰ Responding to this example, Timothy Radcliffe graciously replied *"perhaps we have not won as many victories as we think."*

²²⁰ I should emphasise that none of these theologians talked of progress in terms of treatment, or social stigma, and even less any developments in theology, as though the challenges of HIV and Aids had been resolved. As already stated above, each of them conveyed to me their own sense that there is more to be learned. Neither did talk of progress made or as Timothy Radcliffe termed them, 'victories won', dominate the conversations. To the contrary, this acknowledgement of advances in social attitudes and medicine was mentioned more in passing as the backdrop to the present HIV scene. I dedicate space to presenting the issues raised for me here, not because any theologian emphasised progress or development over ongoing challenges, but because of the uncritical way in which this narrative of progress was presented and my strong reactions to that tendency across all these interviews, and how that has influenced this research.

I shared my 'suspicion' in some of the interviews that the lack of talk about HIV between friends might reflect the social status and relative stability of their friend's lives, and the length of time since diagnosis. A person who is loved, educated, meaningfully employed, in their own home, with good social networks of support, is more likely to have adjusted to 'living well with HIV' than the asylum seeking woman whose only network of support is her local fundamentalist Christian community, or the young unemployed gay man who has been rejected by his Catholic family. I wondered whether it was possible that these friends had simply tired of talking about HIV? Or perhaps social convention prevented them from sharing their deepest concerns, after all no-one likes to be in the company of a person who continually speaks about illness and suffering. Even if one can point to some people living with HIV 'successfully', can we extend their experience so that it becomes a generalizable description of what living with HIV means? As I suggested in the introduction to this thesis and will argue further in chapter six, I think that HIV progress narratives cannot be accepted uncritically. Although I had not formulated my argument when these interviews took place, I had a hunch that talk of how far we have come as a society and in the Church, might be obscuring, helping to keep hidden, the reality of suffering in the lives of people living with HIV. It was a gut feeling that stayed with me.

My conclusion now is that my disturbance was felt not because my interviewees' narratives of progress are not valid, but because they were not congruent with my own experience in pastoral ministry. The feeling of protest arose in me because my involvement in CAPS' ministry keeps the suffering of others current and real, too fresh in my experience to be relegated to the past.

Of the principle benefits for me in conducting these preliminary interviews was that these conversations provoked uncomfortable responses in me, which became an important locus for personal reflection and inquiry. The uneasy feelings stayed with me, nagging away, until I made some sense of them. I kept returning to them: what was it that disturbed me and why? As I continued to ponder this question, and as I contrasted these interviews with the later interviews with Christians living with HIV, one of the main justifications for this research became clearer to me. Narratives of progress-made were placed in stark contrast with the painful experiences that I listened to. My perception that the current reality for Christians living with HIV in England, and by extension in any Western context, is not

understood as the experience of actual suffering that it is, was strengthened. This research can be justified because it seeks to amplify the voices of a still hidden, voiceless, and therefore misunderstood group of people who are members of the body of Christ.

To put it differently, if these accomplished theologians who advocate for those living with HIV, held a view that Christian people living with HIV suffered less than others have in the past, because the situation for people living with HIV has improved, then other people are likely to be equally misinformed. As I will describe in later chapters, for the people living with HIV that I have interviewed the suffering remains an important aspect of their subjective experience, notwithstanding the fact of more effective medicine or a more tolerant societal environment. My interaction with these theologians convinced me that I could not presume that HIV as a contemporary site of suffering, in England as well as other poorer countries, would be understood. This being the case, in the argument that follows I had to give some account of the actual suffering intrinsic to any HIV diagnosis. I began to form the view that the reality of suffering within the experience of HIV in the body of Christ needed to be revisited and revealed in fresh ways. I will expand upon this argument more explicitly in chapter six.

4.9 Vulnerable sharing

Listening back to these interviews I am reminded of how, at this early stage in research, I had hoped to discover some nugget of intellectual brilliance upon which I could hang my research. My initial disposition was to seek answers from these experts. I think this indicative of my own naivety at the time. As van Manen (2014, pp. 28-29) argues, phenomenological inquiry is primarily a method of questioning rather than one which arrives at answers or determinate conclusions. Perhaps the rigour of theological inquiry is to be measured not by the answers that are arrived at but by the new questions generated.

In terms of the quality of the dialogue, the distinction between interviewer and interviewee which I had intended to maintain became less clear. Each interview felt more like a shared inquiry into faith. Each person shared very personal experience with me. For example, Ijey Ajibade spoke about members of her own family who have died of Aids and the impact that had on her. Of the 11 questions in my pre-interview material, only 1 referred to personal faith. My interviewees might have avoided sharing more private detail if they had wanted to. Their responses could have been restricted to matters of doctrine for example. I think

this also reveals something meaningful, and leads me to risk an assertion about how theological inquiry into HIV should proceed. For these people at least, encountering HIV has always demanded and included a deeply self-reflective dimension. Whilst the issues raised by HIV in the church are intellectually challenging, until and unless this challenge is also felt to be personally disruptive, the veracity of any claim to have reflected theologically upon what it means to say that the body of Christ is living with HIV and Aids, is contestable.²²¹ To put it another way, academic inquiry into the theological meaning of HIV requires that one become vulnerable to the ways in which HIV disturbs our existing convictions, beliefs and even our own sense of identity.

I have just argued that theological reflection upon HIV ‘demands’ something from us. I use this word deliberately. I mean to reach beyond the widely accepted turn to experience as a source in academic theology (Schnier, 1992; Lane, 2003, pp. 7-19). It is possible to draw from the experience of others in such a way that maintains an intellectual distance – one can study experience and use it to make an argument, whilst remaining personally unaffected. For each of my interviewees, and in my experience, the most important theological insights have been born of moments of personal encounter which have caught us unaware, and stayed with us on an affective level. Like my ‘nagging feeling’ referred to above, these feelings demand to be noticed and reflected upon. I am suggesting that when a theologian uses the experience of others living with HIV as evidentially authoritative, the credibility of any conclusions reached, and the reliability of the accounts they give, depend at least in part, upon their own transparency about how encountering HIV as a lived experience has also changed them.

In Chapter six I will give examples from the interviews with James Alison, David McLoughlin and Sebastian Moore, of such personally disruptive and theologically productive encounters, in the prelude to my main argument. Christina’s dinner party experience above, is another example of what I am naming here, and shows how even in ordinary otherwise unremarkable situations an encounter with HIV can leave a lasting impression which is

²²¹ This point relates to the reflexive turn which assumes that our efforts actually constitute an involvement that changes us (Todres, 2011, pp.11, 31; Smith et al., 2010, p.35; Swinton and Mowat, 2009, p.34 – 36, 60) discussed in the methodology chapter.

never forgotten. As Kevin Kelly succinctly put it: *"People sharing their experience is what tends to have a big impact on you, rather than theoretical things."*

4.10 Listening to stories and the theological implications of 'Grace encountered'

Again, each of the theologians emphasised how their exposure to HIV had impacted them personally. Usually this was named with reference to particular meetings with people living with HIV or dying from Aids. Whatever larger theological or philosophical issues might be raised by HIV as a global pandemic, it was the encounter with individual people that stayed with them, and prompted them to think about more abstract theological concepts and reflect upon their own way of being Christian, as Christina Beardsley did in the example above.

Kevin Kelly was typical when he told me that HIV and Aids *"...affected me massively really. It has affected me as a person, and that doesn't go away."* The enduring impact of HIV on these theologians cannot be overstated.

Kevin was convinced of the continuing need to reappraise approaches to moral theology. As I have already noted experience as a theological source is accepted today. Nevertheless, Kevin identifies a tendency within academic theology, or at very least a legacy of previous approaches, that is a contributory factor in the stigma attached to HIV:

"[Stigma] is due to ignorance and some due to prejudice...and people being judged for their conduct, which comes back to moral theologians, and how we tend to be focussed on ways of conduct rather than on people's lives as stories and developing stories." (Kelly)

To illustrate his point he told me about an encounter he had with a woman he met in the Philippines when working with Cafod. Elsewhere he refers to this encounter as an 'exposure experience' (Kelly, 1998, pp. 20-21). The young woman had been forced into prostitution so that she could support her family.²²² Almost inevitably, she had become infected with HIV. As Kevin told me about her and all the hardships she had endured, his voice conveyed incredulity and admiration:

²²² As with Ijey above, Kevin recognises that this woman had little or no choice in the circumstances.

“Some people’s lives on the outside, they might look, well there are question marks. But on the inside, there are miracles, miracles of growth in the circumstances they have lived... While I was listening, I thought to myself, I am listening to a saint talking here.” (Kelly)

This is further evidence of how personal experience is a key theological issue methodologically. Kevin’s example challenges the theologian to let go of any approach which proceeds as an assessment of behaviour set against abstract doctrine or even the most firmly held objective moral standards. It surely asks that we put aside any preconceived legalistic judgements. Why? Because listening to, and being fully present alongside people who share their stories has the potential to open a sacred space within which a person is changed at a deep level. Julie named it explicitly as:

“...the experience of Grace...most of the time...we find Grace a very difficult concept, we can’t quite put our finger on it, but occasionally, bang, we know that we are in the presence of Grace, because of the personal encounter...something about that moment...the mystery of the Divine, that ineffable something that is usually experienced rather than thought about, you get a bang, a lightning rod of connection, and that is what happened for me...that theologically, is what happens when...the Divine is made very powerfully present...a kind of profundity of love which is all that Grace is really.” (Clague)

Of course, God’s Grace may be encountered without the preconditions that I am suggesting. As with Christina’s experience at the dinner party, and Sebastian’s experience later, in chapter seven, sometimes God’s Grace breaks through despite the apparent certainty of one’s own moral position. Isn’t this what happened so dramatically to St. Paul on the road to Damascus?²²³ However, insofar as any theologian has the ability to make a rational choice, openness to the God of surprises by way of deep listening to the stories of others, especially those who suffer, is preferable over a more certain disposition or fixed theological stance.

In terms of this study, such a choice includes an element of risk-taking in faith. Such a theological stance assumes that within theological research, God is at work, and may be encountered within the process of research itself. As a process of inquiry which proceeds in

²²³ Acts 9:1-22

conversation with other Christians, it takes seriously the proposition that where two or three are gathered Christ is also present. As a shared journey in faith, it assumes that graced encounters in the Spirit are not only possible but can be expected between us.

“The first thing you’ve got to do is find the questions that perplex you, and then of course you’ll have to ask everybody’s help to find the answer. The people whose issues you are addressing are also your partners in conversation. If you go in already knowing the answers, well even God does not have much of a part to play. I have learned that often one must reach out in love, unsure of how to answer questions, but confident that in good time, the Lord will speak in one’s mind and heart.” (Radcliffe)

Here again, it is the experience of a shared journey in faith that is described. It is an approach which begins with wonder (van Manen, 2014), allows for ‘not knowing’ and requires patience. It is deeply respectful of others and treats their experience not merely as data to be used or studied, and is open to an encounter with the Divine, which is revelatory and transformative.

4.11 Summary and conclusion

In this chapter I hope to have provided the reader with a sense of the tone and quality of the preliminary interviews with theologians. Space does not allow a full account of each interview in detail. Rather, I have highlighted those themes which are important theologically and methodologically for this thesis, situated within my process of learning.

Above, I stated that I had three objectives when I commenced these interviews. With reference to them, I will try to summarise the key learning points that I took from the conversations with the theologians in total.

First, all the main theological challenges were raised by us. I have described in this chapter how suffering contextualises the ambiguous theological landscape out of which all the questions arise. However, I did not identify any new or emerging theological issues, of which I was not already aware. I recall feeling slightly disappointed and encouraged by this outcome. I was encouraged inasmuch as it served to confirm that there were not any major gaps in my understanding; but disappointed that I did not discover any ‘nugget’, a piece of new writing, or wholly original question, which would provide me with an obvious direction for further research. Rather, these conversations served to confirm that the issues with

which the Church has been confronted since the pandemic began, remain as challenges that we have yet to respond to adequately. Those insights and lessons from HIV which have been written about theologically already, are still with us as unfinished business: Timothy Radcliffe's assertion that HIV has awakened our sensibility as to the way people can be marginalised is debateable in view of the fact that exclusionary practices continue in the churches; HIV stigma is still stubbornly present amongst us; Kevin Kelly's exhortation that HIV teaches us that we must be 'pro-women' (Kelly, 1998, p.63) and challenge Patriarchy, are words that await action. These are just some of the more obvious examples.

Second, I learned something about the balance between listening and inquiring, and sharing my own thoughts in the course of a semi-structured interview. The quality of conversation as a shared exploration of faith, felt appropriate. The sometimes confessional tone that occurred in these interviews often in surprising ways, as with Christina Beardsley above and Sebastian Moore following in chapter seven, indicated that we had created conditions of trust. This trust that existed, with the respect they afforded me, and the 'academic humility' they modelled were relational qualities that I learned from and which I would seek to replicate in my later interviews.

Throughout this chapter, I hope that the primacy of experience for theology is abundantly clear. The personal experiences that each of these people shared with me, and their emphasis on their own growth in Christian faith through 'graced encounters' with people living with HIV, strengthened my resolve to rely upon a methodology that would privilege the encounters that I would have later with my principle group of interviewees. I felt encouraged to abandon any quest for a theological question or category that would frame further research more narrowly. Rather, I decided to trust that open, non-directive questions that invited the sharing of personal stories, in the context of a shared exploration of faith, would illicit rich theological and spiritual insights.

The prospect felt both exciting and scary. If a specific theological thread of inquiry had emerged forcefully in these preliminary interviews, I might have felt more secure in terms of the academic task. But, as Sebastian Moore cautioned: *"Being a good academic theologian does not necessarily make one a good theologian."* Nevertheless, it may have felt more manageable to pursue the opinions of people living with HIV about this or that doctrine, or

use the writing of one theologian as a basis for a thesis.²²⁴ I imagine that I might have been clearer about the direction of theological travel; more assured about the question if still open to a variety of possible answers. However, as I have argued above, theological inquiry into the meaning of HIV demands vulnerability. I was conscious of taking the more risky methodological approach, and one which would require patience as Timothy Radcliffe suggested. And to pursue the meaning of HIV through the stories of others without any proscription was more consistent with my stated aim to uncover *their* faith-sense, and amplify *their* theological voices. This represented a strengthening of my commitment to a methodological approach which privileges the experience of people living with HIV.

This also represents an act of faith that I want to note explicitly as central to my theological approach.

“Together we shall find answers to moral questions, with the people concerned, attentive to the tradition and to what new word God will give.” (Radcliffe)

What might be discovered by taking this statement seriously? This is what makes a stance of theological openness to HIV exciting. What new word might God give if, as sisters and brothers in Christ we pursue the questions together? How will Christ become present within an environment which is truly respectful and attentive and open to the Spirit?

As Kevin Kelly put it: *“Truly academic theology is about listening to people. Making experience sense of faith and faith sense of experience. It is so key.”*²²⁵ Julie Clague referred to HIV as an invitation to *“plunge into the deep end”* of a theological pool when more often than not we stay safely in the shallows, and Timothy Radcliffe used a similar image: *“Often we are theologically too timid, to ‘go into the deep’; I don’t think good theology is done unless you go out of your depth.”*

So, I resolved to continue my research by listening to the stories of others as they would have them told. More than anything else, from these interviews, I became more convinced of the value of the theological methodology which I have chosen; the centrality of

²²⁴ As examples of the alternative methodological approaches I mean see Reimer-Barry, 2008 whose inquiry into the lived experience of women with HIV centred on Roman Catholic doctrine of marriage; and Leclercq, 2010, who constructed his excellent theology of vulnerability and HIV with specific reference to the work of Enda McDonagh.

²²⁵ Kevin Kelly was referencing a phrase he took from Jack Mahoney.

experience and the transforming power of Christian encounter; and the willingness to trust uncomfortable feelings and wait on the Spirit, in a vulnerable place. I felt encouraged to move in the direction of the deep end.

Chapter 5. Introducing Christians living with HIV.

5.1 Introduction

The previous chapter has described the process and outcomes of preliminary interviews with theologian-practitioners. In chapter three the theoretical basis and preparation for these interviews has already been presented. Like chapter four this chapter also functions as a kind of bridge between: the theory of chapter three; the vast theological landscape revealed in my conversations with the theologians; and the lived experience of HIV for these interviewees. I introduce the reader to the people at the heart of this study, describe each person in brief, and present some of the stories they shared with me. For the most part, I resist analysis at this point. I want their stories to be received by the reader and their voices to be heard before my own. My theological argument that these experiences can make faith-sense when viewed through the lens of the Passion of Christ will follow in Part II. At this point I invite the reader to enter into the experiences of my interviewees through their own words, as far as this is possible.

Again, I think it important to situate this chapter within this study in two ways. First, I want to be clear about the purpose of these interviews, and the significance of these conversations for the process of my research. Second, I intend to be explicit about how this chapter functions as part of this thesis.

Methodologically the previous interviews were designed to elicit theological themes and were conducted using academic theological language. As I noted in my discussion about the quality of those interviews²²⁶ the personal encounter with HIV that the theologians shared, turned out to be as important for this research as any theological category or doctrinal statement made. What HIV means for each theologian both in terms of their own Christian life, and their understanding of what it is to 'do theology', was uncovered via the more personal sharing in the light of faith. Learning from this, and by contrast, this second set of interviews followed an inverse process. I began by inquiring into experience in the light of faith, and waited for 'the theology' to emerge. None of the seven questions that I used to structure the interviews included any academic theological language. For example, I might

²²⁶ See 4.9 Vulnerable sharing. For example, questions such as 'what does the phrase the body of Christ living with HIV mean' or 'what are the main theological themes'.

have asked what the phrase ‘the body of Christ living with HIV’ meant, but I avoided doing so, lest I impose a theological category or direction that did not originate from the person before me. I approached these interviews on the assumption that if conditions of trust could be established, then each conversation had the potential to be a graced encounter within which the theological voice of each person would be heard. Taking Kevin Kelly’s assertion seriously, my approach to this task of academic theology started by listening to people’s stories. Again, I was still totally unsure about the ‘theological direction of travel’ at this stage, but was committed to an approach that empowered each person to share their reflections upon experience in whatever way they wished. Taking Timothy Radcliffe’s point seriously, that making faith sense of challenging circumstances or events in life is something that can be approached together I consider this chapter to be evidence of a process of collaborative theological inquiry out of which the argument I make in Part II has been co-created. As I argued in chapter three, these interviews commenced with a further important assumption based upon faith: that ‘when two or three are gathered in Jesus’ name’ Christ is present, the Holy Spirit is alive and God ‘speaks’.

Second, what follows should be qualified in the same way as the previous interviews. The descriptions below are snapshots, and unless explicitly stated otherwise the detail given is from the time of the interview. The people introduced here may or may not hold the same views and beliefs today. Not all of the voices will be heard evenly. What follows is an account of the conversations we had from my perspective.

More importantly, I intend that this chapter functions for the reader as a thorough introduction to the people who have contributed to this study. It can be understood as the beginning of an encounter with these people living with HIV. There is a great deal of data that is not included.²²⁷ Below and in Part II what is shared by all my interviewees are experiences of suffering. I have had to exclude many instances of suffering in the stories that I was told even though so many of them might have been included. Nevertheless, they may be considered fuller accounts than many examples or ‘case studies’ presented elsewhere. In short, this is because these are not ‘case studies’ in a narrow sense. I

²²⁷ For example, I have not included information about Cate’s relationships with her children and her former husband in any detail although this was important for her. Neither do I mention Tiago’s failed attempt, to be ordained as a Deacon in the Roman Catholic Church, although it too would be of interest to many readers.

approached each person with the absolute determination to avoid 'voyeurism' or an approach that might result in the person feeling commodified. To re-emphasise a point made in chapter three, I had a privileged access to each person because of the relationship I had with them through my pastoral ministry, and these interviews proceeded upon the basis of a shared inquiry in faith. The theological argument that I make later has not come from myself alone as one who assesses or analyses others who are studied and observed. Rather, at the risk of repetition, each of these people agreed to share very intimate details with me because they thought it would be helpful and good for the wider church. Every word originates from the context of these relationships as sisters and brothers in Christ, and a conviction that there are members of the body of Christ living with HIV who are ignored, misunderstood, suffering and isolated. What follows are instances of courageous faith, and I will return to just how much courage is required to speak in chapter six. Theologically speaking, I cannot claim sole authorship. Insofar as there is anything worth saying in these pages, it is the fruit of the Holy Spirit present during the graced encounters called interviews. I think it important therefore that the reader gets the fullest possible impression of those who have generated this study with me.

Throughout my intention is not just to make a theological argument, but to provide any reader with a type of encounter with HIV as a lived experience. As I argued in my introduction, as we heard in the last chapter, and as will be repeated again, it is not theological argument so much as embodied encounter which affects any person. As most people living with HIV in our church communities remain hidden, one of the justifications for this study is that it attempts to reveal something about God through revealing something about these individual people who are members of our one body of Christ, and yet remain for the most part unseen and unheard. This chapter then, is more explicitly, an invitation to meet these brothers and sisters properly for the first time. These accounts are important insofar as they contextualise the experiences I describe in Part II, when I develop my argument that living with HIV in the body of Christ can be understood through the theological lens of the Passion of Christ.

I referred in the previous chapter to the bewildering and confusing spaghetti junction of theological signposts that confronted me. During this set of interviews, I listened to a similar tangle of emotions, and pain, and faith, and love, in the stories I was told. At the time the

challenge for me was to stay present patiently, and not allow my own anxiety about how I might make theological sense of these experiences to interfere with my listening. It is a matter of doing justice to each person that what they shared and entrusted to me is listened to respectfully. In a similar way this chapter can be understood as the proper start of the reader's encounter with these people. I will conclude this chapter with a summary of what I took from these interviews that helped me to formulate the theological argument that follows.

5.2 Meeting the interviewees

Cate

Cate is a white British 51 year old woman. She was infected with HIV on 26th December 1994 as a result of *"one burst condom"* with her partner, whose HIV positive status she was aware of. She was diagnosed on June 16th 1995. She is open about her HIV status, and has agreed to use her real name. I interviewed Cate in her Housing Cooperative home, in Liverpool. Cate is a contributor to the 'Positive Faith' project. She is a poet, and is occasionally commissioned to write for disability arts projects or magazines. Her first anthology of autobiographical poetry 'Climbing Mountains in the Dark' was published in 2009 (Jacobs, 2009). Of equal importance is being both a mother to her three adult children, and a grandmother. At the point of writing Cate is in training for ordination to priesthood in the Anglican Church.

'Feeling connected' to the Divine has always been important to Cate. In chapter eight I will return to Cate's intense 'mystical' experience, following her diagnosis. The quality of relationships and the sense of a shared spirituality, experienced within a community of believers, have been more important to her than denominational distinctions. Her journey in faith has taken her from the Anglican tradition, through Pentecostalism, via Roman Catholicism, a period of disconnection from any organised religion, before a return journey to church, which began during a Positive Catholics retreat weekend and led her 'back' to St. Brides Anglican church, where she now worships and is Church Warden. She was raised Anglican, but remembers feeling somewhat disappointed by her confirmation aged 12: *"I was really expecting something quite incredible and dramatic to happen when the bishop laid his hands on me...something deeply spiritual that would change me forever, and it didn't happen. So, I guess when I was a little bit older, that was what I was looking for, that*

experience of something that would really change me in profound ways.” She made a friend who attended a Pentecostal church and, despite the disapproval of her parents Cate underwent what she calls a *“Believer’s baptism”* around the age of 16yrs old. *“I was going to take on...Christianity...consciously making that choice for myself...and had the full immersion experience, still expecting that something quite amazing was going to happen.”* For a second time, Cate was left feeling underwhelmed: *“Yet again, I was pretty disappointed, all I got was soaking wet. And it wasn’t long after that that I floated away from the Pentecostal church and towards the Catholic church where the charismatic renewal was happening. And I think there was something about a familiar format, but more movement of spirit within that, that I found attractive. It was about tangibly being able to connect with what we would call the Holy Spirit, and that became very important to me.”* She was received into the Roman Catholic Church as an adult and married a man from an Irish Catholic family background. They were both active within the Charismatic Renewal movement. He told Cate about ‘liberation theology’ and they shared a passion for social justice. Cate was active in anti-racist campaigning and the peace movement. The marriage lasted for 10 years, and ended in divorce. The process of marriage annulment within the local diocese was deeply distressing and offensive to Cate. In part this led her to feel alienated from the Catholic Church.²²⁸

Cate understood the emergence of HIV and Aids as a justice issue. She decided to *“get wise, get informed and stand up and be counted.”* The common perception was that Aids affected firstly gay men; followed by African immigrants; haemophiliacs; and intravenous drug users; as something that affected ‘others’ not at all like her. That Cate, a young mother in her early 20s, was so aware is remarkable. She was motivated to show solidarity with these groups, and because she realised that HIV *“was going to affect me and my generation if it hadn’t done already, it was always on my radar.”* About 1992 Cate trained as a volunteer for the Merseyside AIDS Support Group.²²⁹ It was here that she met Simon,²³⁰ her own marriage was ending, and two years later they began a sexually intimate relationship. *“I*

²²⁸ Cate’s experience of the marriage annulment process and extracts from this interview are included in Manning, 2015.

²²⁹ Later renamed ‘Sahir House’ HIV support agency, which is still operative in Liverpool today.

²³⁰ To protect identity ‘Simon’ is a pseudonym

knew when we came into a relationship together that he was HIV positive. I really wasn't fazed by his diagnosis."

When they met ARV treatment was not available. Cate imagined how different things might have been, if they had met just a few years later. There was a lot to consider: *"I had just come out of a marriage. Am I ready for a relationship? I have 3 small children, is he going to be part of our life? What would that be like? So there were lots of considerations that were not about HIV, for me, certainly. I think it was a very big consideration for him. So it was quite a gradual and slow coming together really."* Notwithstanding these shared concerns, their relationship developed and Simon became integrated into the life of the family. Simon lived with Cate and the children, and *"he had something he had always dreamed of. He really did love my children, and they really did love him."* But it was not to last for long. Two diagnoses, one for Cate and another for Simon, would change everything.

Whilst making love to each other, a condom broke and Cate was infected with HIV. *"Simon was fairly crest-fallen when he realised, he was like 'go and get a shower, go and take a wash' so I did just to make him feel better in the moment. But a bit of me was going, when it's too late...And by the New Year I had become really quickly ill, sero-conversion. A really serious bout of flu, and then the chronic fatigue that went on for ages afterwards. There was always that little voice in my head, I knew, I just knew."*

Despite Cate 'knowing', her doctors refused to consider HIV as the possible cause of Cate feeling so unwell. *"The doctor tested me for everything he possibly could, knew that Simon was HIV positive, but, I still didn't fit the picture...there did feel like there was a lot of stereotyping going on, almost like, well, women like you don't get it!"* Eventually, she went to a hospital for a same day HIV test. She couldn't pick up the results as she had to collect her children from school. The following day her diagnosis was confirmed by the clinic nurse. *"And then the difficult thing...how do I go home and tell Simon, because he didn't even know that I had gone. I hadn't told anyone, so everyone I told after, it was a huge shock...there was that feeling of picking up everybody else's devastation and not necessarily having a space for my own."*

Within months of this Simon was diagnosed with Aids. CMV was attacking his eyes, and he was going blind. He was in and out of hospital and became increasingly unwell. He had not reacted well to Cate's diagnosis. It was a difficult period for them both: *"Simon was in his*

own spin about my being diagnosed...He was completely and utterly devastated...and quite quickly after that, just caught up in his own being diagnosed with Aids. So, yeah...It was a pretty shitty time...I was struggling to come to terms with my own diagnosis. The fact that I probably wasn't going to live to see my children grow into adults, and...[my partner] was in this dying process. So, two massive turning points happening together. And he turned away from me...and our relationship deteriorated..." Just over 2 years later Simon left the family. He returned to his mother's home where he died about 8 months later aged 39.

The children knew Simon was unwell and would eventually die, but he didn't want them to know about his or Cate's HIV status, *"because he felt, and these are his words not mine, 'that they would see him as the man who murdered or killed their mother'. Very weighted, strong words, and in fact when I did tell them that was the last thing that they thought."*

Cate has regrets about that. 18 months after Simon died she told the children the truth: *"I can look back on that now, with huge compassion...It does always make me really sad that that he didn't have that kind of reconciliation with them, and that he died with that feeling of guilt, really deep guilt....I never blamed him for it, it happened in a moment of love. And there's no blame to be apportioned...when I told [my children]...their reaction was...'You are our mum and we love you', they've stood right by me, and they would have stood by him too, and it makes me sad that he didn't have all the love he could've had."*

Cate's experience has heightened her awareness of excluding attitudes within the church: *"There is something about prejudice within faith, and religion...at its deepest level.... with the silence that people feel that they have to keep, about their status or sexuality, or both. That sort of pushing out to the edge...The one place where we should...find compassion and acceptance is often where we find judgement, is often where we find exclusion..."*

HIV has *"flung"* Cate *"out to the fringe"* and made her amongst *"the untouchable"* ones. Following the example of Jesus, Cate wants to share with others *"A way of life that is about lovingness, that's about acceptance, that's about healing; about feeding each other when you're hungry...about caring, about giving a damn...the fact that [God] has made me the way She has, with the gifts and abilities that I have and that strong sense of social justice, why would I not find God within this, and stand up and be counted, [be] seen and heard, in order that others may also come in from the edge. Come in from that place of silence and secrets...allowed to be who they truly are, without fear of judgement."*

Gloria

Gloria insisted that she be described as a woman living with HIV and nothing more. This was the only interview undertaken in a place that was not either my home, or the interviewee's home. At the time Gloria was renting a room in a shared house. Gloria was concerned that she may be overheard or we may be interrupted if we met at her home. She wanted to avoid any need to explain to her house-mates who I was, or the purpose of my visit. So I booked a neutral room to use locally in the city where Gloria lived.

Gloria has attended Positive Catholics retreats, and it is because she knew me and trusted me, and had encouraged me to undertake this study, that she was willing to be interviewed. Nevertheless, we spent almost 10 minutes discussing how the interview notes and recording would be used, and stored. I explained to Gloria that both would be kept securely and we agreed that the recording would be erased after I had used it for the purposes of my writing up. During the course of the interview she revealed descriptive characteristics, necessary for understanding a story or a point she was making. Some of these descriptors are included here with her consent. The attentive reader will form a picture of Gloria as a woman and of her circumstances, but respecting her wish, I will not include here any further details about Gloria's age, relationships, sexual orientation, or profession.

There is no doubt that Gloria wished to protect her personal information, and needed reassurance from me that there would be no unintended accidental disclosure of her HIV status to others. She was an intensely private person. Her attendance at the Positive Catholics retreat weekends allowed her to be with others without hiding the fact of her HIV status, but beyond this, she rarely revealed her diagnosis. When someone inquired about her health, which was not unusual, as she was often in severe pain and had great difficulty walking, she explained that she had meningitis, without further elaboration.²³¹ However, it was also a point of principle for Gloria. Her reflections on faith and her theological arguments did not require the sharing of more personal detail, and should be received or rejected, on their intellectual merit. That Gloria held this position so strongly reflects her resistance to what she considered the voyeuristic inquiry of others into details that they do

²³¹ Meningitis is one of the Aids defining illnesses, and globally remains a major cause of death in people with HIV (Williamson, P. R., 2017).

not need to know, and her experience as a woman in the Roman Catholic Church. It was this interview that caused me to think more deeply about the questions that people living with HIV are routinely asked about how they were infected with HIV, and why this is so problematic, which I explore in chapter six. In chapter eight we will hear more from Gloria about her experience as a woman living with HIV in the Church.

Gloria was critical of the Church's negativity towards the body and human sexuality. She understood this as having roots in a tradition which has upheld monasticism as an ideal of Christian life: *"If one takes the monastic life as the norm, [it] is one which is built on the denunciation of the world. I think [it] has an important place in the Christian tradition, but it is not the place for all. To deny the goodness of a loving sexual relationship between adults, is to deny one aspect of what it is to be human: to be an incarnate soul. It is going back to Augustine's view of [how] original sin [is transmitted], which is not being challenged enough."* This model of Christian life that Gloria names as 'denunciation of the world' tends towards a dualism which denies the goodness of the body and is suspicious of physical intimacy. In Gloria's opinion this body-negative emphasis in teaching and doctrine *"misses a trick...because we are incarnate souls...there is something really powerful about being sexually intimate with another human being, which also makes us vulnerable but also allows us to express and experience love, in a very embodied way."* Gloria was not simply proposing that we replace one inadequate ideal that formed the attitude Sebastian Moore described previously as 'disgust with the body' with another. She was not talking about a naive romanticism where everything is sweetness and light. But she was insisting that the sex-negativity with which she had been raised is life-denying because it inhibits learning what it means to love and be fully alive. Rather than viewing sex as something bad or dangerous Gloria proposed that we *"focus on what is good, about human sexuality. How it enables us to experience and, offer, love, to one another, with the awareness of human fallibility, of power relationships, of sin as well, but still, seeing it as a good. As an intrinsic good of human being [that] teaches us how to be human."*

Gloria found her diagnosis to be *"traumatic, and what one has to go through after HIV, is often traumatic. And so in that sense, yes, it affects faith."* Understanding our life with God as something pursued over against the world, was not an adequate way for Gloria to make sense of her own faith. She wanted Christians and theologians to speak teach and act in

ways that recognise that love is discovered, vulnerability experienced, and suffering endured, physically. In our bodies we feel all that hurts and requires healing; through our relationships with others we learn what it means to be fully human. *“One can imagine that physical suffering is as a result of original sin and if we, as human beings can do something to overcome that physical suffering, if we can think of salvation as healing, bodily healing as well as soul healing, then, I think a lot more people would listen to the Church.”*

As we ended our time together Gloria said: *“Thank you for giving me this opportunity to speak.”* I thanked her in return, and she replied, *“It has been my pleasure.”*

Gloria endured a great deal of suffering, physically, psychologically and spiritually after being diagnosed. More than anyone else in this study, she endured the affliction of an HIV diagnosis in an ongoing and constant way, which I will describe in chapter eight. The last time I was with Gloria I helped her walk 100 yards from her home to the ambulance which took her to the hospice where she was finally relieved of her suffering and died from Aids related diseases in 2016.

Rosie

Rosie is a 45 year old black Ugandan woman. She lives with her husband and their two teenage boys in a Council flat in South London. She works as a live-in carer for elderly or disabled people. Often this requires her to spend weeks away from home. She was diagnosed with HIV in January 1997. She describes her present health as *“not excellent but good. Although I have some pains from sickle cell as well. Sometimes my eyes turns yellow, sometimes my body turns yellow.”* She is an active member of her parish community. She attends Mass several times a week, and Confession regularly. Rosie is an active member of Positive Catholics. And often introduces new people to the group. She keeps in touch with others regularly to offer support, and will visit members who are unwell. Rosie is also a contributor to ‘Positive Faith’.

She was baptised as a child into a devout Roman Catholic family. *“Every night we have to say the rosary or my mummy would not be happy.”* The youngest of nine children, only she and her eldest sister are alive, seven children having died before Rosie was born: *“I just saw their names on the grave.”* Both parents were respected figures in the rural village that Rosie grew up in, as was her sister who was the local teacher. Her father, a peasant farmer,

died in 1972. Her mother continued to work their small piece of land, to raise money she would sell yams in the local market. She did not have the means to pay for a secondary school education, so after primary school, aged 12, Rosie joined the local Franciscan convent in the hope that she could further her education and become a religious sister.

She discovered that her prospects were limited. *"I will be the one who is doing the laundry, looking after the cattle, I will become a nun, but I will be doing the housekeeping bit because I don't have any qualification. So my mum decided 'you are still young, we can do something'. So she saved some money, she sent me to a technical school, where you can go and learn practical things."* Rosie completed a two year typist course before returning to religious life. This time she joined a community of Benedictine sisters and took vows.

However, this community could not send Rosie for further study either and she spent most of her days digging in the fields. Rosie was concerned to advance herself, not only for personal development, she realised that without making her own situation better somehow, she would be in no position to help her elderly mother. She requested permission from the Mother Superior and was allowed to go back home to her village while she thought about her future. *"So they took me to the parish priest to hand me over, so that they could keep an eye on me, that's what they do normally. And then like once a week, one sister could come and visit me, make sure I am still alright, to see if I had changed my mind and was coming back."*

Rosie stayed at her mother's house. This was the first time that she experienced being ostracised by her community. Her mother was not happy that she was thinking of leaving the convent, and Rosie's return to the village was considered shameful: *"They saw it as a failure, or somebody not to be talked to, so I didn't have no friends...the girls in the village would not come to see me, they would not, because I had left the convent."* After some weeks, Rosie met some English religious sisters, based in Kenya, who were in the area promoting vocations to their community. She told them about her frustration and that she wanted to find a new community where she could gain an education. They told her that they would return to Uganda in a month. So Rosie told the Mother Superior of her decision to leave the convent permanently, and her intention to join the Grace and Compassion sisters (G & C). Rosie wanted to leave 'properly' so the bishop was called: *"we go to the same place where I did my final profession, I was sad, and then he came and took of the*

habit and took off the belt, and then I just got my ordinary head wrap, and then I tied it, and that was it. Some sisters were crying.”

Rosie visited the G & C sisters in Kenya and stayed with them for 3 weeks, and later she was invited to join them. But Rosie did not have money for a passport or the visa which she would need to live and work in Kenya. So her mother sold some cattle. This was how, after several years Rosie came to live and work in their home for the elderly, in the south of England aged 25, in 1993. Three years later she would leave the vowed religious life for the last time.

Her mother's health was failing, and her house had become derelict. The parish priest kept writing to Rosie, seeking help from her for her mother. Concern for her mother overwhelmed Rosie. Feeling that she was getting no help from her community, she began *“a mini-protest...When the Superior came she said ‘what do you think you are doing?’ I said I am sleeping! ‘You didn’t go for meditation. You didn’t come for the office. You didn’t come for Mass. You didn’t come for breakfast.’ I said you know yourself, my mum, is homeless. So I was sort of, rude...I didn’t get up for the whole day.”* After further discussion, Rosie was permitted to visit the family home in Uganda, and upon arrival with other sisters from Kenya, they found her mother in real poverty. Rosie refused the offers for her mother to be looked after at the sister's nursing home in Kenya. She felt that it would be a source of gossip that her mother, *“whose daughter was a Nun in England”* was unable to provide for her. It would be shameful sending her mother into a situation equivalent to destitution. Rosie refused. *“We’ve got a family grave, who will be going to dig that grave? We’ve got land, so my Mum’s not going, end of. So I suddenly started not really listening to anybody, and that’s how I started.”* Back in England Rosie continued her protest. *“By then...I started becoming aggressive.”* Rosie let out a long sigh, as though exasperated: *“then, I said I have just had enough and I need to look for alternative for pay to help my mum out. I came out.”* Rosie left the G & C community in early 1996.

She stayed with a Ugandan family in Oxford, and found a job as a server at MacDonalds. She stayed in close contact with the sisters. Within months Rosie had sufficient money to visit her mother, and repairs to the family home began. *“My mummy was shattered seeing me in civilian clothes. She said ‘but they looked after you’...I said I am not joining any other community. ...I tried to reassure her, I will do everything I can to help you.”*

Back in England Rosie met her husband, and became pregnant. At this point she received her HIV diagnosis. She also suffered the loss of the baby through miscarriage. Remarkably, she was advised by nurses not to tell the father about her diagnosis for fear that he would abandon her. Nevertheless, Rosie informed him. *"He said 'how can this be? In the Convent, do they also have sex? How can my wife be positive? That can't be happening'. Then when he was tested he was negative, I said, thank God."* Rosie was devastated, and returned to stay with the G & C sisters for 10 weeks where they cared for her.

By 1998 Rosie was pregnant again and she gave birth to a healthy baby boy at Christmas time. To celebrate this and the completion of improvements to the family home, her mother threw a party on January 1st 1999, at which she was poisoned and died. *"I absolutely shattered. I regretted, I thought, why did I leave the community."* As the boy was born by caesarean section Rosie could not travel for her mother's funeral. *"She is dead! She had not even seen the child! It put me in pieces."*

Reflecting on all this Rosie says her faith in God was tested. *"If really God was there to guide me, or to protect me or my mum, at least if God would do me a favour, and let me go home and let my mother see my child...Even now, if I go at home and I see the graveyards...it makes me angry. It's not worth it, is it? All my effort...like He raised me up although we were poor, and sometimes I think...where is God? Sometimes I think God is not there and then I go back and I sit down and I pray and I say God is there...I normally I do appreciate what God has done for me. He has kept me up. God had ups and downs but here I am!"*

Lazarus

Lazarus is a 61 year old black Zimbabwean man. He was baptised as a child into the Roman Catholic Church. His work as an Engineer took him to the UK in 2000. He was diagnosed with HIV in 2002. He lives with his partner in Surrey, and is employed as an Engineer. He is also an active member of Positive Catholics, a contributor to 'Positive Faith' and regularly leads peer support group meetings.

Lazarus has always had a sense that he is special. All his friends had several brothers and sisters but his boyhood was unusual. *"I was the unique one, as the only child."* Attending a Jesuit run Catholic boarding school at age 11, he was an able student with an independent spirit. He took his faith seriously, and he began to question the faith he had received from

his parents. Daily Mass was obligatory. Lazarus challenged this. He argued that compulsory attendance was contrary to God given free will and if, once coerced, a pupil sat feeling resentful and angry, was this not the school pushing the pupil into an occasion of sin? The rules were relaxed and the obligation to attend Mass became weekly not daily. Lazarus was angered by what he viewed as some teachers' self-serving behaviour: *"some of them did not live up to my expectations of the church leaders, and this led me to questioning, how people in those positions would be able to behave in particular ways."* When he left secondary school he *"had quite a negative attitude towards religion. I started questioning things that happened within the Church. I did not get very satisfactory answers and this led me to drift away from the Church."* He went to a teacher training college. Here there was no expectation of church attendance, much less that one should pray or be interested in religion. *"It was then that, I realised there was a void in my life, and out of my choice, I started going back to church. It required commitment, to get up early, when the others were sleeping, and go to church, and then walk back from church. That's where I felt, there was something missing, and I started going back to church."* Lazarus took teaching positions in Zimbabwe and then Botswana. Although these were not Christian schools he became involved in providing extra-curricular study groups for the students. *"To help them and guide them to live in a Christian way, being considerate to the needs of others, and not being selfish. I fostered this spirit in the school[s] where I taught."* Aged 30 Lazarus had a career change. He enrolled on a training course in Mechanical Engineering, and studied in Malta. He enjoyed his time there. He pursued a new career and felt *"at home"* in the Catholic culture, and attended church regularly.

After 4 years he qualified and returned to Zimbabwe where he began work in his new profession. He met and married his wife, and they had two children. They both had a Catholic education but he also raised them with a keen sense of personal responsibility. Lazarus chuckles when he tells me that he is expecting grandchildren now, and that both of his children still go to church.

Lazarus had worked in the UK for two years as an Electrical Engineer, when his wife arrived on holiday in 2002. During this visit she became unwell, and whilst attending hospital she received an HIV diagnosis. *"So, the doctors asked me if I wanted to take the test and find out, and I agreed"* he breathed out a long heavy sigh, *"to take a test. And knowing the*

relationship I had with my wife, and our intimacy, when I got the result, I was not too surprised. What surprised me though was I did not have any illnesses, or any indication I might be infected." His wife returned to Zimbabwe and Lazarus remained in the UK. I will revisit Lazarus' initial reactions to diagnosis in chapter seven.

He told no-one about his diagnosis, and feared confiding in his parish priest: *"I wasn't certain what the reaction would be – I was afraid I might be ostracised, turned away because I would be judged."* Yet he needed to understand what it would mean. Joining a support group he drew hope from the experience of others. He still had a future, life would continue. He also listened to stories of terrible sicknesses and wondered why he had not suffered as others had. Making faith-sense of all this was by no means straightforward for Lazarus as I will show later. However one conclusion that he arrived at was that *"God had a message for me, because He had spared me the problems that the others had...there must have been some protection. My diagnosis reinforced a sense of being taken care of by God."* In turn, this motivated him to do something for others and he volunteered for a series of medical research trials.

Lazarus became involved in volunteering with an African HIV agency. It was not long before he was asked to assist in a poster campaign aimed at African Muslim communities. *"They had tried high and low to get people involved, to [appear in] posters and publications for awareness within the Muslim community. And they couldn't find anyone. And they asked if I would be willing to step in. This is a situation that needs addressing, and someone has to step up so that people get engaged, and not let their faith stop them from a chance for, for life. So there was a photo shoot where I stood in as an Imam."* Lazarus laughs as he recalls friends ringing him in disbelief. *"What is going on' they asked, 'have you become a Muslim?'"*

For some African Christians, particularly within Pentecostal churches, there is a potential confusion between having faith in God and adherence to ARV medication. *"They were getting conflicting messages"* he tells me. Lazarus was involved in undercover research to discover how often church members were being told by their pastors to rely on 'faith healing' over modern medicine. He uncovered evidence that some people had died because they thought that relying upon medicine showed a lack of faith in the god who cures those with sufficient faith. He helped devise a training kit for use in churches, *"[to] educate people*

living with HIV [about] the advantages of having one's faith and being on medication" and assisted in the development of a curriculum for seminary training in the Anglican church "so that they would be able to address these issues, and be able to speak openly about them to their congregations."

Through the support groups, and his activism, Lazarus became more accepting of his HIV status. However, he needed more than medical knowledge and activism. *"[Support] groups...only looked at health and medication...There is a spiritual dimension that needs fulfilment, and I did not find this in the secular groups...it was an integral part of me that had to be addressed, and I found this with Positive Catholics. I thought, oh, this is more like where I belong."* In chapter nine we will hear how Lazarus experienced healing through his membership of Positive Catholics.

His activism continues. He gives talks and presentations for CAPS. His 'secret' is out, and Lazarus is amongst the most publicly visible of African people affected or living with HIV in the country.

There are three further points which arise from his experience of public speaking and have special relevance for this study. He highlighted the unthinking judgment that he has experienced when he reveals his HIV status to other Christians: *"You are not acknowledged as an individual...Very often...the first question they ask you is 'How did you get it?' But that's not relevant. It is an illness. Like anybody else's. It's not a question of how you got it, but what can we do to move on from there? Helping you out, preventing the spread of HIV. Issues like that. And working together to build a society that is tolerant of people in various conditions."* In chapter six I will argue that this question has significance and meaning for people living with HIV and for the reader of this study.

Second, Lazarus is convinced of the value of sharing experience openly and honestly within the church. He laughed out loud as he recounted the following incident at a conference where he was due to speak: *"I met a group of Catholics, and they were curious to know what Positive Catholics meant. They thought maybe these were Catholics that were better than other Catholics. I explained this was not the case, we are all the same, but we have got an extra challenge in our lives that we live with. And we want to share, with you the challenges that we face so that you can understand where we are coming from. And perhaps together we can work to assist and help other people who are suffering in silence."* Lazarus

acknowledges that this may be challenging, but insists on the value of encountering others who are different from oneself: *"I think, like everybody else, the church might want to avoid unpleasant experiences and situations, but what the church has to realise is that those experiences can only enrich us, by opening our minds to them and gaining experience of them....The church has to recognise the existence of people living with HIV, because we are part of the body of Christ, just like anybody else. We have a role to play within the church, and we should be acknowledged...We have a lot to give the church."*

Third, he identifies the *"...biggest issue about being Christian and living with HIV is the silence that you get from the churches..."* which reinforces HIV stigma and isolates people living with HIV. Lazarus continues to speak into the silence.

Finally, as we ended the interview I asked Lazarus to sum up where he finds God in the midst of HIV: *"Living with HIV is a challenge. For me, it has opened my mind, to see the presence of God in my day to day living. I do not know how best I can put it. I acknowledge that everything that happens in my life, there is God's hand, directing where He wants me to be. I think He has got a purpose for me to fulfil, and achieve. He keeps me in the fire, and burning. He is with me, in all things."*

Paul

Paul is a 38yr old white British man. He was baptised as a child and raised in a traditional Irish Catholic family. He was infected with HIV through contaminated blood products used to treat his haemophilia. He is a teacher in higher education. I visited him at his home in a quiet cul-de-sac in a typical English village where he lives with his wife and 3 children under the age of 10.

Paul's parents agreed that it would be better not to tell him. He was just a little boy. How could he understand? How could they bear to tell him? Who knew how soon it would be before he became sick, or how long he had left to enjoy his childhood. It was 1983 *"the height of the Aids epidemic and the stigma was at its ultimate peak"*. Paul was one of three cousins in this extended Irish Catholic family diagnosed with HIV.

Paul considers his situation unusual. Not only because he is a 'long term survivor', but also because as a haemophiliac, he is within a relatively small sub-group of people living with HIV, and other co-infections, in the UK. He describes his health as manageable, but as *"a bit*

of a pickle for me.” He was also infected with “Hepatitis C, and A, and B, and I’ve been told more recently that I am also at risk of CJD.”²³² He describes how internal bleeding makes his joints swell up, and over time erodes cartilage causing intense pain. As a result, three years ago he underwent an operation to strengthen his ankle: “they pinned my ankle to my leg, to try and stop further joint damage...Unfortunately...with the HIV there was an infection, and I ended up losing my right leg, [amputated] below the knee. So yeah, everything kind of interacts with each other unfortunately.”

Growing up Paul recalls: “I had a very strong faith...It mattered to me that there was a God and there was a Jesus.” Being told about his HIV status as a teenager challenged both his faith and his strong sense of Catholic identity.

“[The diagnosis] completely changed all my beliefs in every way. You know, my perception of me as an individual, my relationship with the world, my faith. Everything altered...at the time I didn’t appreciate the significance of this news. I didn’t realise what it could mean in terms of things like starting a family, relationships with people, because I was, you know, I was on the edge of sexual maturity...it was like a bomb that hit the ground and didn’t go off straight away. It had the timer still going, and it went off later. It was tricky to say the least.”

Over the next 10 years Paul finished school and eventually he received a Degree. However, he had to change universities, and his study was interrupted twice. At the second university, he suffered with severe chest infections and had to withdraw for one year until his health stabilised. Previously, in his first academic year, his mother visited him at his hall of residence, just before Christmas. The news that one of his cousins had died from Aids was devastating.

“I only found out when I was 16, it’s not as easy for you to relate to people at that age and he was a bit older than me. So I was kind of on the cusp of getting to know him a bit more, unfortunately he died...It was my first year away at University, I was about 19. It was a massive shock, partly because it brought home the realities of what could happen, and also upsetting because it is someone who is identical to you, partly family and someone with Haemophilia and HIV. Also, I wanted to start having conversations with him about things I

²³² Creutzfeldt-Jakob disease (CJD) is a rare, degenerative, fatal disorder which attacks the central nervous system.

couldn't talk to my parents about. Maybe things like relationships or sex or things like that. So, yeah, that was really tough."

Afterwards Paul remembers feeling intensely lonely, and he found it hard to relate to people. He kept his HIV status "...incredibly quiet, incredibly secret." His Catholic identity and understanding of faith was shaken. His remaining cousin, a little younger than himself, was not someone to whom Paul could turn. They were not as close, even though they had a "...kind of unspoken bond..." This cousin had drawn some conclusions of his own about God, faith and religion.

"I remember my cousin saying to me 'you don't believe in all that nonsense do you?' He says, 'if there is a God why has He done this to us?' And at that time, you know my faith was stronger and I thought no...bad things happen to good people; there is no logic, no reason why it shouldn't..."

Processing all that HIV meant took many years. When his mother told him that he was HIV positive Paul was dismissive at first. In the interview he referred to notes from his first consultation with his doctor after he had been told.

"So this was [when] he would tell me about it, and tell me about the risks, and what to do and what not to do...there's a line in the letter, and I think it's quite telling and quite upsetting in some ways to look back and read this, bearing in mind how old I was. The doctor has written, 'I asked Paul if he had any questions for me. He said he had only one, and that was will I be able to have a family?' And that was it. So, I think it kind of shows that from the time of them telling me, when I wasn't bothered, to that first time with the doctor, things were starting to twist, the cogs were starting to go round, and I was starting to process it."

The 'five stages of grief'²³³ can often be observed in the responses that people have to an HIV diagnosis. Paul recalls the anger that surfaced, and how societal attitudes, reinforced by his Catholic upbringing, provided him with a scapegoat.

"...it was really difficult to process all the information...I was just angry as well, I was away from home and angry. And this ties in with the Catholic identity as well, you are after

²³³ Kubler Ross, 1981. *On Death and Dying*.

somebody to blame. I remember, one of the groups I was incredibly angry with was gay men. Partly because [of] Catholicism....in some way [they were] responsible for my HIV."

This takes us back to the question that Paul's cousin raised. If God is not to blame then who is? Paul's anger raises questions of guilt and innocence. In chapter seven I will return to describe how church teaching and an emphasis on sin in Paul's Catholic upbringing, contributed to Paul's captivity in an unhealthy state of anger for several years.

It is important to recall how children like Paul were depicted in the popular press at the time as the innocent victims of a terrible disease. Paul feels fortunate to have had a good education which has helped him to alter his view of his own and others HIV status, but which has also created distance between him and the Catholic identity that he was so attached to as a child: *"I'm lucky...I've had a good education, and you start to question things as you get older..I've started to read more into the area. And I've questioned my Catholic faith a lot more. And I just don't buy that homosexuals are evil or different from heterosexuals...over time I've moved away from the Church's teaching on that."* As for the innocence within which Paul's diagnosis was framed, he is adamant now that *"...there is no such thing as an innocent victim, it's all just rubbish. No-one deserves to get HIV."*

Paul was raised with a very strong sense of his Irish Catholic identity, and this was based largely upon a pre-Vatican II understanding of what it means to be a *"good catholic"*. As an Irish Catholic myself, I recognise the same emphasis on a rigid obedience to Church teaching, and the pride one has in belonging to a Church that somehow makes a person special, definitely different, and morally superior to people of other faiths or none.²³⁴ One of the losses Paul experienced is the loss of his particular 'good catholic' identity, and that was

²³⁴ I recognise that this may be a distinctive feature of an Irish Catholicism within the context of immigrant status in England. Nevertheless, and whether or not this constitutes good theology which obviously it does not, in Paul's story that such a culture exists and such beliefs are still held is evident. For example, I was slightly taken aback when this highly intelligent man referred to his wife and her family, as demonstrating to him that goodness and kindness are possible beyond the boundaries of Catholicism. *"She was not even baptised into the Church of England, but her family are really nice people."* Or when speaking about Islam, *"there is one God, whether you call Him God or Allah or whatever, it is just one being. I shouldn't really be saying that as a Catholic, obviously"* Paul betrays a particular cultural-religious formation. His rejection of what he understood as Church teaching in regard to condom use was another point of conflict for him, which contributed to his crisis of identity as a young man.

painful. In chapter eight I will argue that such a formation creates a crisis which must be worked through if faith is to survive.

Paul's view of what it means to be a 'good catholic' also has the effect of excluding him from his local parish church today. His understanding of what is and what is not acceptable in church is reinforced by silence as much as by speech. It silences Paul too. Turning to the church for support hasn't felt like an option. *"In the Church HIV is associated with homosexuals, so you've got stigma; HIV is associated with sex and in that way with promiscuity, so that's a big no-no. I just wouldn't feel comfortable about disclosing my status...It's easy for people to make judgements...it would really upset me, people judging me as a person, because I just think you just haven't got a clue, you have not got a clue. And I am not just talking about me, I don't want any sympathy, I am thinking about other people, gay men with HIV, black Africans with HIV, children with HIV. It's just not as clear cut as the Church would like to paint it, it just isn't."*

For Paul, the church is simply not a safe place. This member of the body of Christ does not think the community capable of accepting or understanding him.

Despite the struggles Paul still identifies as Catholic. It is so bound up with his sense of himself, to abandon his Catholicism *"would be like cutting away a part of my identity."*

Paul's faith is still a comfort to him. When he was admitted to hospital and lost his leg, he still ticked 'Catholic' on the admissions form. He received Holy Communion every day and attended Mass. He chooses to believe. There is a God who matters to him still.

Piramo

Piramo is a black Ugandan man aged 51. He lives in a council flat in South East London, and regularly attends his local church. He was diagnosed with HIV in Sudan in 1994. He has lived in the UK since 1998. He is divorced from the mother of his two sons, one of whom is grown up and lives back in Uganda. His younger son, a teenager, lives with the mother also in London. He is currently seeking employment. He has a Bachelor degree in accountancy. However, it took 10 years for Piramo to obtain 'leave to remain' from the British Home Office which creates a sizeable gap on any curriculum vitae. He is smartly dressed and clean shaven, the kind of man that would wear a tie and polish his shoes before leaving home to pop down to the shops.

Piramoï was baptised as a child and grew up in a Catholic family. His parents instilled in their eight children the 'Golden Rule' of Christian life *"...that I should do to others what I would want them to do to me."* With a broad smile he explains that the pseudonym he has chosen, after his grandfather, means *"Praise"*. As a teenager he took a keen interest in the Bible. His voice is full of enthusiasm as he tells me how he discovered scripture as something living and relevant: *"the Bible...encompasses every aspect of life. It interprets everything that we do, what life is all about is there in the Bible. I was reading the Bible a lot."* He remembers in particular how he began to understand scripture as more than stories about the past, but as God's continuing promise to liberate God's people, with implications for his life now. He noticed how so many biblical stories tell of God's people being set free from situations of oppression, but this always requires that people act: *"Coming from an African background, you are always faced with upheavals, refugee life, displacement, all sorts of social and human calamity. And often man-made calamity or injustice. You have to seek redress for the situation in which you find yourself...The appeal is, do something to set yourself free, if you feel that you are being done wrong."* Throughout this interview Piramoï's recurring theological theme is one of trust in God's constant friendship.

His route to London was a matter of life and death for him after he was diagnosed with HIV whilst living and working in Sudan. At 26yrs of age he had travelled to Khartoum to study for a degree, and had intended to return home upon completion, but there had been a military coup, and Uganda was gripped by violence. His family warned him not to return, so he stayed in Khartoum and found a job there. In his mid-30s he became worried. There was little accurate public health information but *"the knowledge was there about HIV. People were talking about it, and what the symptoms are."* He had been feeling sick, and rashes had appeared on his skin. *"So, looking back, at the time, the signs and symptoms, is when I realised I could have been HIV infected. So that was the point of suspicion."* Piramoï decided to get tested at the hospital, and was diagnosed in April 1994.

The basic counselling from medical staff was helpful, but he knew that there was no access to effective treatment in Sudan. *"I remember, at moments when I was alone, in moments of self-reflection, quietly and intently praying for God's blessing and God's support. God should give me the strength to deal with this, and that God would provide an opening for, towards a way in which I could get treatment for this infection."*

Piramoï needed to access treatment, somehow. He knew that advances in medical treatment were being made in the West, so when he was required to visit the London office of the firm he worked for, he took his opportunity and claimed asylum in 1998.

In the weeks following his diagnosis he remembered *“what the Scripture says, if all else fails we have God who we can turn to.”* Piramoï had no-one else to confide in. He feared rejection from his friends if he told them about his diagnosis, he had seen others ostracised after their HIV status became known. Even a person who was seen in the company of anyone living with HIV risked being *“shunned”*. Friendships were important to him, and he could not risk losing the everyday support and companionship of his friends or his church. *“It is fear of being infected and also fear of being associated. Because already the prejudice is there against people with HIV, so, if you are seen with one, then probably it also means that you are one...It was the same thing [in church]. It’s the prejudice...if you told anybody, told your close friends, told your close family members, they just would not understand...instead of recognising that you had a problem as a person and need support, people would just abandon you as a close person instead. It was not wise at all.”*

Piramoï could still speak with God. *“I was praying more, in churches, and also in personal prayer...more than before...It was good, and it is good, and will always be good to seek help through prayer from God. I have maintained that more frequently than before I was diagnosed...That was quite a significant change.”*

He never considered HIV as a kind of divine punishment. He was clear in his acquittal of God using the ‘free will defence’: *“If we go wrong it is not because God makes us go wrong.... God gives us our life!...most important God gives us the free will to choose how we live, what you do, what you don’t do. I think that is crucial, that is precious.”* He was less ready to acquit himself and questioned whether or not his HIV infection was the consequence of failing to live a better Christian life, what he called *“the blame game”* to which I return in chapter six. Piramoï now considers that debate to have been ultimately confusing and unhelpful. He moved beyond it pragmatically.

“I just came...to realise, ok. I am here where I am now, the only way, the only thing to do is, what is sensible for a Christian to do...Pray that God can bestow upon me...every support that I will need, every spiritual help that I would need. So that would strengthen me to move on.” God’s part is to remain *“...always present, ready to help us...you know, if you need me I*

am here...we should realise that we can always turn to God to help us...To find some way of healing and move on."

Francis

Francis is 43 years of age. He is a British born white gay man, and has a partner. He owns his own home, and works full time in a Public Policy development role. He was baptised as a child to Irish Catholic parents. He was diagnosed in 2008. He has had a keen sense of spirituality all his life.

"My faith has always been integral, I think, to my identity. That isn't faith in terms of a particular faith tradition, [but] faith as a disposition or a fundamental way of being. It has always been behind all of my thoughts about, my career, my relationships, my sexual orientation, my station in life, the meaning of my life, and what I do. It gives my life meaning. It has always been there in the background."

Throughout, Francis uses the words faith and spirituality interchangeably. For him faith is made up of a set of beliefs and the religious teachings and practices that follow from a Christian world view. His faith is important insofar as it shapes his sense of personal spirituality. From an early age he has understood spirituality as constituting more than a set of beliefs or practices. Rather, spirituality relates to how he is as a person, his identity and his way of being in the world. *"[Spirituality] has never been peripheral to me it has always been right at the core of how I try to live."*

His quest for spiritual perfection began as a little boy, shaped within his Irish Catholic family at home, in rural England. He served at Mass on Sundays and remembers playing with his sister, saying Mass. He would be the priest, of course, his sister a devoted parishioner. As he read the stories in Butler's 'Lives of the Saints' he was inspired by how their faith and way of life led to a personal transformation that not only made them into extraordinary individuals, but had real impact in the world. *"I was incredibly interested in mysticism when I was around the age of 10-12yrs old. That whole approach to your life really, that faith and spirituality is not something that you do on the side, it's something that totally forms who you are as a person...it wasn't always something 'up there' and in heaven and away from the world...really spiritual people...are transformed individuals in the world, not only in terms of their own identity but also in terms of what they can do for other people and the impact*

they make in the world.” In imitation of the saints Francis set himself “penitential tasks” and considered whether one day he might become a priest. Later he attended university and obtained Bachelor and Master degrees in theology. “I was interested in trying to answer some of the important questions about life and it’s meaning and...give my faith a degree of intelligence and understanding.”

Francis’ mother introduced him to the Charismatic Renewal prayer meetings, *“and that made a really massive impact on me.”* Francis drew comparisons between this form of prayer and the mystical experience which he sought: *“a very physical experience of faith, not just in my head. Emotional, adrenalin, extraordinary.”* He was impressed by the services of healing that he attended. Speakers emphasized how important it was for the church that a connection with the healing power of the Holy Spirit be recovered. *“It is something that defines the attraction and charism of the early church. Just as important as the sacraments and preaching, healing is something that needs to be integral to the experience of Church.”* Aged 15 Francis recalls slipping away from home *“secretly”* to attend healing services: *“I got prayed over...twice...And I am not quite sure what I was looking for...The whole idea around healing, which is about a restoration of your integrity or, [I went] because I think a call to healing is integral to most people on a faith journey...healing is right at the heart of a Christian’s experience in terms of coming to wholeness, coming to terms with your memories and your past.”*

I pressed Francis to say more about his secret trips to these healing services. He carried a burdensome nagging doubt about himself that first entered his consciousness two years previously whilst reading the ‘New Life in the Spirit’ booklets that were popular within the Charismatic Renewal movement. *“I [came across] the...quotation from, from St. Paul, and it was something like, ‘adulterers, fornicators and homosexuals, will never inherit the kingdom of God.’ And this was the particular way in which that passage was quoted. And I don’t think I understood my sexual orientation fully...but for some reason that absolutely was the most visceral, like, spear, through my heart, when I read that. I remember that day, and I can remember being really troubled by it. I felt that it [related] to me.”* In chapter seven I will return to how issues of sexuality and conflict with church teaching for the gay men in this study, give particular shape to a cross of self-loathing; the pain of which is acutely felt after diagnosis. Reflecting upon this experience Francis thinks that *“in my teenage years...the*

whole issue of my sexual orientation was coming to the fore. Suddenly something so important to me, which was my growing spirituality; I was really troubled by the fact that, oh my God, I might not be, in spite of all my spiritual aspirations, I may be excluded by virtue of something that's about my identity as a person, from participation in the Kingdom of God. And it really really worried me, it really vexed me."²³⁵

Francis' HIV diagnosis came as a tremendous shock. *"I started to write everything down because I was really worried that I was going to completely fall apart"*. He wanted to keep a record. He was unsure what the next days and weeks would bring, or what he might do. A diary may help him in the future to make sense of what was happening, and was a coping mechanism at the time. Francis had *"this real fear of physically, emotionally, totally losing the plot, really quite frightening."*

He had recently started dating a Muslim man. They were getting along well and he could see a future for them in a committed relationship. Francis' previous relationship had ended eight months earlier. The break-up had been difficult. Francis was keen to have a fresh start. He went for an HIV test because of his concern for his new boyfriend, who since the death of his father had responsibilities for the family business and a large extended family as 'head of the family'. *"I really need to be careful here because if there is something wrong with me, then I don't want to put him at risk. A really odd kind of logic really, but I remember thinking, if there's traction in this, I need to be satisfied that everything is kind of all right."* Later, Francis' new boyfriend tested negative for HIV which was a relief to them both. He wanted to continue the relationship, but the intimacy that had begun was cut short because Francis could not bear the thought of exposing someone that he might love, that he had begun to love, to the risks of HIV infection. Francis explains how his diagnosis had a spoiling effect in terms of his capacity for intimacy. *"I went through a phase when I just didn't want to think about sex, or countenance anything like that at all....that was why I ended the relationship quite quickly with the Muslim guy...I thought I cannot do this, I cannot do this, because the*

²³⁵Patrick Cheng (2012) writes about a similar experience when as a teenager he first struggled with his own emerging awareness of same sex attraction and referred to The Catechism for guidance: "Struggling to understand my budding attraction to other boys, I turned to my local public library for help. Being a devout Roman Catholic, I found a reference book on Catholic doctrine, and I furtively turned to the entry on homosexuality. There I learned—to my horror—that I was not only a sinner, but that I was intrinsically disordered. I shut the book in shame, and my relationship with God was never again the same."

sense of intimacy or excitement or whatever, had just totally been tarnished by this experience, I just can't get my head round it."

During this time of turmoil Francis had an experience of healing and peace that came to him in an unexpected way. *"The most amazing thing happened", Francis laughs. "I'm not sure if you will want to report this for purposes of your research. There was a guy that I had been seeing, on and off, [casually], fairly infrequently. And I told him, because I knew I had slept with him over that summer, so I told him. And, he said 'Oh, I've been meaning to come round'. So he came round and we had a bit of a chat, and he said 'well it's not me Francis, because the last test I had was negative'. And so then I thought, well, that's ok, that's all very well. So then I thought he was going to go home".*

As he remembers, Francis laughed again, with delight, and his voice rises in surprise.

"Instead he just goes, 'well are we going to have sex or not?' And I just thought, 'oh, alright then' and so...we went to bed. And it was the most affirming thing that anyone could have done, for me. I remember writing about that, and realizing that was probably the single most affirming thing anybody could have done for me." The single most affirming experience that Francis remembers from those early days after diagnosis came through his body, beyond words. Beyond a marriage bed or life-long committed relationship. Francis' 'tarnished' body was held and his spirit soothed, for a while, through the casually encountered body of his friend. Healing experienced in 'sinful' embrace.

Francis' close friends reacted with compassion and understanding. But they did not share his Christian faith. Soon after diagnosis he contacted the Positive Catholics group. *"If it wasn't for my encounter with other HIV positive Catholics, I think it would have been a very lonely journey, and I don't know what the outcome would look like...My spiritual nurturing from other people has been from my peers, from fellow Catholics [living with HIV]."*

Joseph

Joseph is a white Irish gay man aged 54. He lives in central London in a Council Flat. He has many close friends and is currently single. He is employed. He was baptised as a child. He was diagnosed on 21st Sept 1998.

The very soft tones of Joseph's west of Ireland accent, and a slight stutter, belie an inner resilience and a physical strength. He loves to dance. The 'Five Rhythms' dance workshops

which he attends delight him. His face lights up, as he remarks that, when younger classmates need to rest, despite everything he has suffered, he can dance for hours. Somehow, he still dances.

The Catholic faith of Ireland in which he was immersed was never questioned in his family. The Christian values that he accepted as a child remain with him still: *"Having a prayer life, a contemplative life...Seeing Christ in other people especially the downtrodden and underprivileged...These values were always there."* Aged 18 he was consciously *"...looking for a deeper way to live out my Catholic faith."* So he joined the Order of Carmelite Friars. There he learned from the lives of *"...the great contemplative saints....Teresa of Avila and John of the Cross"* and from Therese of Lisieux who had *"...a child-like approach...her way to God was similar to that of a child approaching a loving father, or a loving mother...It was her simplicity which was really appealing."* Joseph left the Carmelites after four, mostly happy years. *"I decided that the monastic [life]...was not for me as a lifelong venture."* He remains convinced of *"The importance of having a spiritual life, informed by the life of Christ. [His] example and the way He chose to live His life while on earth."*

Today Joseph works as a senior mental health nurse. In this demanding role he has developed a practical therapeutic application for the contemplation that he values. He is a recognised expert in delivering 'mindfulness' workshops and teaching the techniques of meditation, within the patient group. Like Sebastian Moore in the previous chapter, Joseph found the writing of Eckhart Tolle inspiring. Through this shared interest they formed a friendship with Joseph supplying Sebastian with other material from his collection of Tolle DVDs. They both regarded Tolle's way of communicating 'mindfulness' as making Christian contemplative practice more accessible to a modern audience. A reader familiar with Tolle will hear resonances as Joseph describes the 'letting go of the ego' and the importance of 'not-resisting' suffering when confronted with death, in chapter eight.

Joseph's HIV diagnosis was the first of three encounters with mortality. Less than six months later he was diagnosed with advanced lymphoma cancer, which also affects the immune system.²³⁶ He had not told any of his family that he was HIV positive: *"My sister was extremely shocked, because the way she found out was when I ended up in hospital. I had*

²³⁶ An Aids defining disease

kept [the HIV diagnosis] back from her for as long as I could, but once I was diagnosed with cancer I knew I had to tell her. And she was really upset...My doctor told me I had 6 months left because the lymphoma was so severe...And then she had to watch me suffer through 6 months of extremely aggressive chemotherapy... It was very unclear whether or not I would survive...and so of course it was extremely upsetting for her hearing that.” A decade later the toxicity of the ARVs used to suppress HIV had damaged Joseph’s liver.²³⁷ As Joseph spoke about this, I remembered my visit to him in Kings Hospital. The room was dark, and he was in great pain. I was with a dying man. It seemed unfair. There was Joseph who loved to dance lying feebly in the bed, in a web of intensive care machinery. He was barely able to acknowledge my presence. We saw each other. I touched his hand lightly. I left him after a few moments with his sister and his closest friend waiting with him. We expected Joseph to die within hours, maybe later that night or early the next day.

Joseph relied on his faith in God during each of these critical events in his life: *“I knew that God was there helping me deal with the suffering, you know, Christ had suffered. He took on our human condition which involved physical pain and suffering, mental and physical. So the fact that Christ had suffered and understood our human condition was there as a, it gave me consolation, and I knew that Christ was there with me during those difficult times. Especially when the treatment, the cancer took over, and it was touch or go whether I would live or die. My faith then really did support me during those critical times.”* His belief in an after-life gave him hope that there was something good to anticipate. *“God would guide me beyond, beyond, the realms of this world should I have to leave this human existence, that, that there was a better place beyond...there was a spiritual reality beyond the physical realm.”* I will return to Joseph’s encounters with death in chapter eight.

After leaving religious life Joseph had lived and worked in Germany for several years. He considered whether or not he would be open to a sexual relationship. He concluded that his *“...sexual orientation and being a practising gay man was not in conflict with my belief in God. So of course that went against conventional Church teaching...My faith never went away and remained important to me. But, I made a conscious choice to live my life as a gay*

²³⁷ In case the question should arise I should note that as a committed dancer Joseph neither smoked nor drank alcohol during his adult life.

man.” It was not long before he fell in love with an American soldier. That their relationship included a spiritual dimension mattered to Joseph: “We would meet on Sunday evenings...and celebrate our relationship and friendship, by going to Mass first, and then going for a meal afterwards. That brought an aspect of spirituality into our love...because he was...raised in a Catholic family...so I just thought it spiritualised our relationship even though it was a gay one. And that really added value and spiritual significance to our partnership.”

Joseph sees his life and faith as a journey. During his time in Germany, and prior to his HIV diagnosis he describes a drift away from the habitual practices of Irish Catholic life, even though he still attended church and never lost connection with the fundamental Christian values. After diagnosis with HIV he has reappraised his faith. He has explored other religions and finds a spiritually valuable dimension in other traditions. Still, he has reconnected with the traditional practices of Catholic faith, whilst understanding that his spirituality is not contained within any narrow boundaries of organized religion. *“I attend Mass every Sunday now...It helps me connect to God, a way of worshiping God in a practical way. So, yes, my HIV diagnosis has ultimately brought me back into the Catholic way of worshiping but I am not limited by the Catholic way either...my faith is greater than the Catholic Church or Catholic teaching...Since diagnosis my faith has taken on greater significance and relevance.”*

Joseph’s attendance at Mass is one way in which he sets time aside to connect with God. However his HIV status is certainly not something he would feel able to share in an ordinary parish: *“I still think there are a lot of judgemental people within the Catholic fold, and unless they have been touched by HIV or Aids themselves...they just would not understand and there would be some judging going on, consciously or unconsciously.”* His identity as a Catholic within a wider community of faith has been supported by his involvement with the Positive Catholics ministry. *“I feel that Positive Catholics helps [me] connect to the Catholic community in a much more profound way...so I am much more connected to Catholics but to Positive Catholics.”*

Martin

Martin is a 40 year old Irish gay man, who now lives in London, in a committed relationship with his partner of 13 years. He is employed as a social services manager for older people. He was baptised as a child. He was diagnosed in 1995 at the age of 22.

Martin was raised in a Catholic family in Ireland. He has several brothers and sisters. He describes his parents as 'not particularly religious' and his father as a violent alcoholic, although Martin himself was not physically assaulted by him. He attended Catholic schools, and was an altar boy, assisting at church services often in the parish and the Diocese. Martin describes his understanding of God as 'a safe thing' during his childhood. Set against the unpredictable and unsafe family home environment, this safeness of God was mediated through his friendship with a neighbour. Martin thinks that she understood that his home life was difficult, and was showing him kindness. He told me that she was different to others. Her distinction lay in the fact that she had once been a Catholic nun, but had left and got married; and that she was now no longer a Catholic, but had become a Seventh Day Adventist. These things made her unusual in the Ireland of Martin's childhood. He also recalls that she was a person who seemed to take her faith seriously: *"She had thought a lot about God, and who God was, and what God wanted from her and she gave me my first [children's] Bible...When I was finished with it, it was well worn. I became very familiar with all the Bible stories. I took a lot of comfort from that."* This friendship with his neighbor, enjoyable experiences of school, the kindness shown to him by local clergy, and his participation as an altar boy in the liturgy, led him to understand *"God was a safe thing."*

At the age of 17yrs he entered the seminary. He had a feeling that he was *"different"* from other boys his age; he enjoyed participating in church related activities, and he had never wanted *"to be a policeman or a farmer."* He had always had the *"desire to be a priest."* Martin's faith *"changed there...I was being taught philosophy and theology, and doctrine and dogma, about what it is the Church believes in, which it didn't seem to me I was taught growing up in a Catholic school, in a Catholic family...it all felt very new to me, very different, but also interesting and exciting, and developed my faith. So it was an exciting time."* Martin explained that in his family and the wider culture of 1970s and 80s Ireland many people either didn't understand, or didn't believe what he was being taught in the seminary. What was expected was that you went to Mass and followed the teaching of the Church. His seminary experience contrasted with what can be called cultural catholicism. *"We were... 'cradle catholics'...and that was that...what we said we believed were just words as opposed to a real belief....We would say, yes this is the body and blood but no-one really believed it...or didn't even realise that they were supposed to believe it...Whereas I suppose*

in the seminary I was being challenged with, well this is what we really believe as catholics; and I suppose it challenged me, well do I really believe it or do I not believe it? And other things, like the primacy of conscience...I'd never heard [about] that before. I had never heard that I was supposed to inform my conscience and follow it."

It was during his time at the seminary that a name for Martin's 'differentness' began to dawn on him. He began to be aware of his same sex attraction. However, *"how I felt sexually, how I felt about other men was not something I'd heard about....I'd never heard the words gay or homosexual...to describe what I was feeling"* and whilst he recognised that 'gay' described his feelings, the silence on the subject *"gave me the sense that it was wrong, that it wasn't something that I could talk about."* When the word gay was used, it was only as a type of bullying. A fellow seminarian would pursue Martin almost daily: *"he would find me...and say 'you're gay aren't you? Why don't you just admit you're gay? Why don't you just tell them you're gay, why don't you just face up to it, why don't you just deal with it'. It was kind of fairly constant for, for quite a while."* After 3 years he requested a leave of absence with the bishop's consent, so that he could consider this issue. After some time away, Martin had reconciled his feelings and decided that he wanted to continue towards ordination. Being gay of itself was not incompatible with the life he intended to commit to. He discussed this with his bishop, and it was agreed that he would return to the seminary upon the condition that Martin was very 'discreet': *"He was concerned about having someone who was openly admitting that they were gay in Seminary...he asked me [if I was] thinking about campaigning, or...being a voice for gay people, or gay Catholics. I could hardly be a voice for myself, never mind anybody else so it wasn't something I was thinking about."*

In his final year, Martin thought more deeply about what it would mean to be a gay priest in the Church. These experiences of having to keep silent disturbed him. *"[being gay] didn't seem like something I could talk about...to the other students. It didn't seem like something I could talk about to the priests in charge...And if I couldn't talk about it in that environment, then becoming a priest and going to a rural parish and being on my own, I certainly wasn't going to be able to talk about it to anyone there, so what...would that do to me as a person? And I thought that I wouldn't want to take that chance, or choice, and so I left."*

He left the Seminary and feeling the “subtle” disapproval of people in his home parish, he felt as though he had failed: “...it felt like I went from being somebody to being nobody.” With job opportunities scarce, Martin made the decision to leave Ireland and make a new life for himself in London. However, his new situation also left him feeling confused and unsure in terms of his faith:

“My idea of God changed then. The idea as God as someone who was safe. Because suddenly my whole life had been turned upside down...and even though it was my choice [to leave the seminary], I had thought I was going to become a priest, and now I wasn’t...Was God playing some kind of a game with me? So I had left my home, my country, my family, my life’s ambition and found myself in this strange land...And, within three months I had become infected with HIV and within three months after that I was diagnosed...my utter abandonment by God was complete. Because...there was no going back. Even if I changed my mind, and became a bit more mature myself, I could not go back. Because whatever about being a gay priest, being a gay priest with HIV wasn’t an option. And I certainly couldn’t go back to my family...” In chapter seven I will return to this time of crisis for Martin and describe how it made him consider suicide. In chapter nine Martin will speak about how this unsafe place of vulnerability opened him to a more mature appreciation of what it means to be a disciple of Christ.

Tiago

Tiago is 39 years old. He is a white gay man currently living in a council flat in a pleasant London neighbourhood. He was born and raised in Latin America where he was baptised Catholic as a baby. He was diagnosed in February 2007. He is currently attending a United Reformed Church.

Tiago still tries to live out the spirituality that he learned from his grandparents as a child. His parents didn’t attend church frequently. He tells me that his formation in Christian life was theologically “conservative”. He attended an Opus Dei run school, and was active in his parish where the priest also belonged to Opus Dei. It was only when he arrived in the UK many years later that he became aware that Opus Dei is regarded with suspicion by some people. He rejects the criticism as based on prejudice. For him, the spirituality of the personal call to holiness lived out in ordinary life, is what matters.

“The spirituality of Opus Dei, I try to live today, is not something I oppose. It is something I embrace...to sanctify your daily life...Whatever you are doing you are a Christian and you have to sanctify your life through your work. That is the spirituality, that is what I went for...To live a good life in imitation of Christ, loving the church, respecting the Church and the Pope, attending to Mass, just being a Christian.”

Aged 18yrs he entered the seminary. He remembers his time there fondly. *“It was a good experience. I also built strong friendships I keep till today, despite differences...That beautiful thing when you can share everything, from the daily life...and sharing the faith and deepening in the faith and in the relationship with the Lord.”* Tiago was unsure about how precisely he should live a life dedicated to God and the service of the Church. The spirituality of Opus Dei as the work of God in the world still influenced him. He was serious about striving for personal sanctity. However, he was unsure that the boundaries of life as a parish priest would suit him, and he considered living as a consecrated member of Opus Dei instead. He could still take vows of celibacy, poverty and obedience, and live with others in a routine of daily prayer and community, whilst working in a secular profession. By contrast, he also considered a life set apart from the world altogether:

“And then the completely opposite, I was thinking about...the monastery...Then I went to the monastery to explore more my vocation to become a Cistercian Monk. Then I was there for about a year, in and out, and I decided it wasn’t the right time for me.”

As Tiago grew into young adulthood matters were resolved for him. He began to wrestle with his own sexuality. His openness about his feelings would lead to a conflict with his religious superiors, and a shocking confrontation to which I return in chapter eight. It was the start of a lengthy battle as he tried to reconcile the many tensions between his Catholic identity and his desire for acceptance within a Church that considers him ‘disordered’. After 3 years Tiago left the seminary. Returning to his parish he was ostracised. Tiago moved to another city to study for a degree. He was now 23 years of age, and began to explore life as an openly gay man. He mixed with others on the small gay scene, and sought a boyfriend. *“I was not being quiet about it. I was very out within the Catholic university.”* But he also needed a space within which he could continue to pray and share Christian life. He did not attend a parish church often, but he did join the university prayer group during the first term at university. Again, his honesty about his sexuality was unacceptable, and after some

months he felt compelled to leave. *"I was living as a gay man, confronting the Church, to the point I had to leave the prayer group when it was too much...I was looking for understanding. And I was condemned for that, I was condemned."*

Tiago completed his studies and in 2006 he moved to London. He attended church occasionally, and always at Christmas, during Holy Week and on his birthday. When he attended Mass he would receive the Eucharist, because he was convinced that his love for men and his pursuit of sexual intimacy was not of itself a mortal sin.

"I was taking communion always because I was, my difference, I didn't believe that was sin, I was not in sin. So there was no impediment to take communion I was not in sin. It was disagreement between the Church and me, but nothing to do with God."

He needed a strong personal faith; he was alone in a foreign city, and he had begun to experience the hedonism of the London gay scene. Tiago could not rid himself of the nagging doubt that he was in fact *"condemned"* not only by the Church but by God too. And whenever he attended Church, these unsettling feelings re-emerged forcefully. The faith that he retained and so needed was threatened by the Church that he loved.

"I had strong faith at the time. [In] my environment at that time, to deal with that [I needed] faith, I had strong relationship between Jesus and myself...Any time the church got involved that relationship was affected. It was difficult for me...I was having all these feelings, of feeling condemned, and it was something [that came] between God and me, that was very clear."

Tiago recognises that these tensions also reflected the incongruence he felt within himself. Amongst his new friends on the London gay scene he appeared totally open and at ease with his life as a gay man. Inside he remained conflicted.

"Maybe at the time I was working on my own acceptance of my sexuality because I was open outside but inside it was something different...I was self-destructive in many ways, because my history, because the teachings, because what I was confronting."

After some months in London Tiago could no longer reconcile the *"opposing forces"* that he felt within himself. He had lived his life trying to conform to the expectations of Church, family, and community. If he was not to feel acceptance and approval within the Catholic community, he would seek it elsewhere.

Something snapped in him. Tiago decided to free himself from all those influences which had constrained him in his life. He created for himself a kind of exile from his past. Tiago takes a long heavy sigh, recalling how emotionally exhausted he felt:

“Everybody was having the right to opinion on what I was doing, and that was all my life. So I stopped letting people to have an opinion on me. I broke up with my partner so I was by myself...It was the perfect time to say, OK, now I will do what I want to do, whatever please me. There was nobody to tell me oh don’t do this don’t do that, it was just me.”

“Whatever it was, I had a breaking point in 2006...When I just couldn’t cope...[I] Lost contact with my family, with my friends, my country, and just, enjoyed, that was it. I did exactly the opposite to what I was supposed to do. So the good boy died and a bad boy...” Tiago goes quiet. *“But I was naïve.”*

He had not even ventured into a gay bar until he was in his mid-twenties, and the gay scene back home was small and secretive. Here gay life seemed much less inhibited and open. What might it be like if he stopped resisting and rather embrace his gay self, in this new exciting society?

“I wanted to, to have the feeling...I wanted to go clubbing I wanted to have fun. Why not having sex? Thinking outside the box! And trying new things...everything was cool. Being gay was not a problem, going out wasn’t a problem, nobody was shouting at me for that. Quite the opposite, my group and my environment became, became that.”

However, there were risks attached to embracing his gay self within this environment and culture. And Tiago was ill prepared. *“I was vulnerable, it was everything, not just sex...That was the first time I tried drugs...I didn’t have experience, I didn’t know what to do. I just did things, for approval...to be integrated into that specific group.”*

In 2007 he received his HIV diagnosis. Within a year Kaposi’s Sarcoma developed. He was physically deteriorating fast. He recognised that he wasn’t dealing very well with his diagnosis. *“So I start [ARV] therapy, I was referred to psychiatrist, and I start working on that.”*

“I was really naïve because even though I was thirty two, I was the eighteen year old boy. The boy that entered seminary, that now was in London in his thirties. He could do everything what he was forbidden all his life. Without any support.”

5.3 Summary and concluding thoughts

A diversity of lived experience is clear in these stories. In this chapter I have offered sufficient information so that what follows may be set within the context of these individual journeys in faith. This chapter acts as a reference point to be reminded of the particular conditions that prevailed when each of these people was diagnosed. It is already clear that one's ability to respond to the news of an HIV diagnosis is related to the circumstances of a person's life and the quality of their relationships. The event of diagnosis occurs at a point in life's journey and is disturbing and disruptive. What is also clear is that for each of these interviewees, faith and religious belonging mattered and was central to how they reacted to and interpreted this life event. Their prior religious formation and experiences are the faith-context within which each of them was confronted with the challenge of an HIV diagnosis. The theological argument that I present next, arises because their Christian faith continues to be important for each of them. In Part II I will continue to describe their experiences of making faith-sense of diagnosis in the days, months and years that followed.

These interviews generated a lot of data. As the previous conversations offered a broad landscape of theological themes that might be explored, these stories reveal a vast range of experience and raise many of the same questions of faith: Questions of sexuality; hiddenness and secrecy within the body of Christ; bodiliness and touch; prayer; doctrine set against faith; guilt and innocence; inclusion and exclusion; sin and judgment; healing; the list could go on.

As I tried to make theological sense of all that had been entrusted to me, I returned to these voices, listening over and over to them. First, I was reminded of how each interview was a 'graced encounter'. I mean this not only in the sense that I was privileged or moved by what I heard, but that the interviewees found the process of sharing their stories to be healing. They often spoke about realising something for the first time, or having enjoyed being able to speak about living with HIV in the context of their faith, an experience which is not usually available to them. Simply being listened to and being understood was cathartic.

Building upon how the theologians spoke about their 'graced encounters', this encouraged me further. Methodologically it strengthened my resolve that in this study the voices and experience of these sisters and brothers living with HIV must be the basis of an invitation to an encounter with Christ who is living with HIV in His body, the church. I consider it a moral

responsibility that they are seen and heard through the pages of this thesis. In this chapter I hope to have begun to fulfil that duty.

Secondly, I was reminded of how each of these interviews occasioned the sharing of painful experience. Just as the question of suffering came up previously with each theologian, so too it is a dominant theme in all these stories. They were not easy to listen to at the time. However, the willingness to listen to experiences of suffering it seems to me is a prerequisite for any theologically meaningful encounter with HIV. Partly because the suffering of these interviewees and others like them has been largely unacknowledged within the church, but also because they cannot be received as they are without an appreciation of the suffering they have undergone. As I argued in the previous chapter, to reflect theologically upon what it means to say that the body of Christ is living with HIV and Aids, in a way that is open to the possibility of graced encounter, requires vulnerability.

Over many months I finally abandoned any remaining thought of pursuing this research via discussion of a particular doctrine, or framed within the work of a particular theologian. Echoing Julie Clague in the previous chapter, making sense of the relatively recent phenomenon of HIV and moving in a direction of 'theological conscientization' in the church, entails the revisiting of ideas, themes and experience that have been written about before, because they are yet to be understood. The challenge is to do so in a new way, and in greater depth. Reflecting upon these interviews over time, what now seems to be an obvious theological direction emerged. Or perhaps it is more accurate to say that these interviews and the stories that I was told were my invitation to consider in a theologically rich way, the Passion of Christ in the light and shades of HIV.

Having introduced the people at the heart of this study, I now turn to my main argument. In Part II I will describe how suffering in the lives of our sisters and brothers living with HIV can be understood as encounters with Christ through the lens of His Passion, death and Resurrection.

PART II

The Passion of Christ living with HIV

We go to them because they are the flesh of Christ, and hence we listen to them as to Christ, we treat them as Christ, and we learn from what they tell us as though we were listening to Christ himself (Luciani, 2017, p.155)

Chapter 6. Prelude to Part II

6.1 Myths that obscure the constructed cross of HIV

Having introduced the people at the centre of this research, I now come to the theological heart of my argument. Throughout Part II the encounter with these members of the body of Christ living with HIV will continue more intimately as I bring their experience to the fore.

Their voices will be heard through a hermeneutic of ‘passionist spirituality’ which acknowledges that the Passion of Christ continues in the world today at ‘sites of suffering’. I will show living with HIV to be one such site.²³⁸ As I relate the experience of my subjects to accounts of the Passion in Scripture, the main argument of Part II is that living with HIV in the body of Christ can be understood as a type of contemporary passion experience. This is the focus of chapters seven and eight.²³⁹

I will describe how the moment and time of diagnosis is a kind of ‘gethsemane experience’. That is, an experience when a fearful reality hits home and cannot be avoided. Considerable attention will be paid to the impact of diagnosis, because it is crucial to what follows. Everything after gethsemane is in some way responsive to this foundational encounter with extreme suffering. It is also important to distinguish HIV diagnosis, as a gethsemane experience, from other similar experience caused by personal loss or suffering. The detail of personal stories will reveal the unique shape and contours of the cross of HIV today and what living with HIV means theologically, spiritually and actually in my participants’ lives.

²³⁸ The term ‘passionist spirituality’ recognises that the Passion of Christ continues in the world today, at ‘sites of suffering’. It is indicative of a theological standpoint and praxis which understands the Passion of Christ not only as a past historical event recorded in Scripture, but as an ongoing reality in the lives of people who are oppressed or neglected. Christ suffering (and risen) is to be encountered in the lives of our sisters and brothers who suffer poverty, violence, injustice and exclusion: they are the crucified ones of today. Insofar as Christ participates in their suffering, it is Christ through them who challenges us to respond: ‘whatever you do to the least of these you do to me’ (Matt. 25:40).

²³⁹ In the text I will use ‘gethsemane’, ‘golgotha’ and ‘crucifixion’ to denote types of passion experience in the lives of my interviewees. I will distinguish between passion experience in the present, and reference to those places and historical events recorded in Scripture, with the use of capital letters e.g. I will describe HIV diagnosis as a kind of gethsemane experience in the lives of my interviewees; and Gethsemane as the place where Jesus and the disciples gathered to pray. I will also use capitals when I draw upon passionist spirituality to claim my subjects’ experience as participation in the ongoing Passion of Christ. That is to say, where I understand their experience as uniting them ‘mystically’, intimately and actually, so that they become the embodied Christ whose Passion continues in the world today.

I will go on to show how diagnosis brings a person to their own 'golgotha', and once dragged to this place of shame, to 'crucifixion' experience. I argue that in the lives of my subjects the marks of the affliction of HIV, and the scandal of the Cross can be witnessed. Through identification with the first followers of Christ, and with Jesus in his Passion, Christ living with HIV may be heard in their words.

Theologically the Passion of Christ and the Resurrection are inseparable. To consider one in isolation from the other is to miss the meaning of the whole story. My argument concludes in chapter nine with experiences that allow for hope after the way of the passion of HIV.

These stories of strengthening and healing begin within that liminal time between cross and resurrection. As I will show, these experiences always restore relationships that are jeopardised under the suffering of passion and cross. A full account of Christian living, with HIV, and empowered by the truth of the Resurrection, is beyond the scope of this thesis.²⁴⁰ Nevertheless, this chapter will describe how my participants have begun to pick up and carry their own cross of HIV in the light of their faith in Christ Risen and encountered.²⁴¹

However, to explore the passion experience in the lives of the participants an excursus is necessary. I am increasingly convinced of the power of two prevalent HIV myths to negatively influence any encounter with HIV. They are so commonly and uncritically held as to be automatic. One is of recent creation the second has deeper psycho-social and spiritual roots. Both are supported by narratives that I think it crucial to critically appraise at this point. As I do so, the voices of my subjects will be heard, so that what HIV diagnosis and living with HIV means for them, begins to emerge. The discussion is also relevant to understanding the ways in which living with HIV as a Christian can be understood as a passion experience, insofar as these myths help to maintain a societal and ecclesiological culture within which the cross of HIV is constructed. My main concern in this chapter however, will be to show how these myths and narratives influence one's understanding of

²⁴⁰ As will be clear each of my research interviews contains painful experience. In much of what follows a level of Christian maturity in faith is apparent. As people who have retained faith in Christ, my interviewees have their own appreciation and understanding of 'Resurrection' as a theological truth. My principle focus upon the experience of living with HIV as one of cross and passion is justified because this painful experience came through so centrally in each of my interviewees' accounts. Another thesis may be written that witnesses to the power of resurrection in the lives of Christians living with HIV.

²⁴¹ Jesus emphasised the necessity of each person learning to carry their own particular cross as a condition of Christian life in each of the synoptic Gospels: Mk.8:34; Mt.10:38, 16:24; Lk.9:23, 14:27.

HIV as a lived experience. I will argue that they must be noticed if Christ is to be encountered, seen, and heard, through the stories my participants tell.

6.2 Viewing-points and openness to encounter

There are two commonly held narratives²⁴² that influence any encounter with people living with HIV, unless and until they are disturbed. First I will show how myths from the past, often reinforced by painful experience, support the current ‘just a virus’ myth; how this leads to thinking of HIV as unexceptional, and why this is problematic.²⁴³ Secondly, the inherited human impulse towards culpability, especially in matters connected to sex, disease and sin, can be so preoccupying that genuine personal encounter is impossible. I call this the ‘guilt and innocence’ narrative.²⁴⁴ Any praxis of presence and ‘being with’ others requires that these narratives are exposed and challenged.

²⁴² By ‘narratives’ I mean those things that ‘we tell ourselves’ and others, and hear from others. Narratives may be spoken or not. Often, they run silently in a person’s mind, sometimes consciously, and at other times less consciously. They are the ‘scripts’ or stories often repeated in the surrounding culture, generative of group-think which individuals internalise. They operate not only at a cognitive level, but affect how people feel and behave with others, or more abstractly exert an influence upon them when considering issues, subjects or topics. They inform or misinform judgments and opinions, and impact affectively and emotionally. Narratives “are templates: they provide us with tropes and plotlines that help us understand the larger import of specific stories we hear, or see in action....We learn these narrative templates from our culture...in the way we might unconsciously learn the rules of grammar at home - by being exposed to multiple individual examples of living stories that rely upon them.” Anne Harrington quoted in Frank, 2012, p.14.

²⁴³ I have written already, in preceding chapters about how this myth has come about. In summary, the first two decades of the pandemic were characterised by metaphors which heightened public fear of ‘the AIDS plague’. These in turn served to blame and demonise PLWH, casting them as ‘alien others.’ This public reputation created additional suffering for those infected and most affected. The fear threatened to deny the humanity of those who suffered. The drive to destigmatise HIV has resulted in a new form of ‘denial’ which also results in the silencing and invisibility of people living with HIV, which causes isolation. The ‘denial’ of HIV as a threat to public or individual health does not remove the underlying fears of those that carry the virus, because of the deep-seated nature in both society and individuals of these fears. This thesis argues that it is only through personal encounter in one form or another that the prejudices and anxieties that are the basis for HIV stigma can be first acknowledged, then confronted and overcome: the degree of intimate encounter correlates with the confrontation with our fears and therefore with the stigma that attaches to the person living with HIV. If this were not so, the provision of factual information would be sufficient to reduce stigma. In the same way that a person who is diagnosed with HIV is forced into an intimate encounter with HIV, and must work through the necessary stages to first acknowledge, confront and overcome the fears provoked in them, so too the body of society (Western society at least, arguably every society) has yet to engage in a process of ‘intimate encounter’ with HIV.

²⁴⁴ These are not the only narratives that arise in relation to HIV, but they are commonly held, often uncritically.

6.3 Noticing ‘just a virus’ narratives

There are many people, well informed through experience, and sympathetically disposed to those affected and infected, who add to the illusion that HIV is no longer an ‘exceptional’ infection.²⁴⁵ Often their recollections of a time when they were more engaged with HIV and Aids is the dominant influence, the ground of experience, which becomes the lens of their viewing-point. They remember the war years. Many of them, now well into middle age, cannot forget the past. They recall the grief as they accompanied a loved one, family members, brother priest, or lover who made the painful descent into Aids and on to death. Others recall an incident or personal story from ministry that stays with them to this day.

For example, in my preliminary research interviews David McLoughlin, academic theologian and Catholic priest spoke with me about how his life was changed forever by his brother’s revelation of his gay sexuality, HIV diagnosis and death from Aids. As he witnessed for the first time the extraordinary love between his brother, his lover and their friends, their way of being with and compassion for each other, David was challenged to notice and reconsider his own attitudes to gay sexuality. Timothy Radcliffe OP, recounted the story of a man dying of AIDS; how food was delivered to him on a tray, pushed into his room on the floor, because hospital staff were frightened to come too close to the patient. The Dominican Community he belongs to felt challenged to respond in a more Christian way. They decided to offer hospitality and respite to affected families in the monastery, and in the wider Dominican family he remembers the sensitivity and compassion with which a brother priest infected with HIV was cared for.²⁴⁶ Christina Beardsley, Anglican priest, recounted the challenge of planning funerals that could include a gay man’s lover and friends, when it was feared that they would not be welcomed by the natural family. Theologian James Alison reflected upon how he witnessed his gay friends die from Aids, and how he lost his fear of Aids and death: *“I have not really been bothered by death in quite the same way as before.”* James remembers the love between these dying men. In his voice I hear compassion as

²⁴⁵ I deliberately choose to consider people who are ‘informed’ and have previous personal experience of HIV to make the point here. I will not consider those whose views are based in simple ignorance of the facts, or those who are younger and grew up in the post ARV period and are necessarily influenced by the ‘just a virus’ myth, if they have had any education around HIV at all.

²⁴⁶ Timothy Radcliffe makes mention of this community response as one outcome of the Spode Conference on the Church and AIDS held in the UK in 1986. He references other experience from this conference in Radcliffe, 1987, pp.115-121; 2012, p.164.

protest, not only 'in defence' of his friends but as an affirming turning point for himself as a gay man: *"Accompanying someone who died whom I loved, one of the things that has been important for me, and it was a grace, was the realisation afterwards that, f*** no, this love is real. This was not some kind of special 'faggy love-lite', this was the real thing. I couldn't any longer be complicit with any attempts to pretend otherwise. That would really be to give false witness."*²⁴⁷

James summarised the feelings of most in this group of interviewees when recalling the impact of years spent with people living with HIV and dying from Aids:

"It was a bit like the first world war. You come away changed from something like that, and people who weren't in the first world war presumably had little idea of what it was like to be a squaddie in the trenches, but those who were in it, certain things did change thereafter and that was that. It had all the risks of being in trench warfare, of burnout and post-traumatic stress disorder, and for a long time I did have that. I only discovered much later, how much that had affected me."

Against the back-drop of their war years, the various dimensions of suffering became personal and real for these theologians through embodied encounters which affected them deeply. They did what they could. Like good Samaritans they did not pass by. However, once the crisis seemed over, they moved on in life, never forgetting, but moving on nevertheless. Past experience shaped them, and they carry it with them as painful learning and insight. Were it not so, the experience would be forgotten. But it is not. Like all important encounters, it stays with them as an aspect of identity, because it changed them. It is hardly surprising that their own intense experience, leads them to say 'it was terrible then, thank God things are not as bad now'. To suggest that the situation is as terrible today as it was in their war years would be to minimise and de-value their experience, and dishonour the suffering of those who lived and died with HIV and Aids before.

²⁴⁷ In recent literature, Vincent Leclercq (2010) feels compelled to explore the vulnerability of PLWH as a theological category in direct response to his encounters in priestly ministry and as a physician. The starting point for Paul G. Crowley's (2005) work on suffering, the cross and hope was his experience of accompanying his brother, coming to terms with his identity as a gay man, and his eventual death from Aids.

It is very important to keep this memory of past passion experience alive. Many theologians have warned that to forget the sorrows of the past imperils humanity and theology.²⁴⁸ We should not forget the past, and the sense that each person makes of their own experience is intensely personal, truthful, and deserves to be honoured (Frank, 2013, p.xiii). However, from my perspective, this viewing-point is problematic. Not because it is wholly untrue, but because it is insufficient. It is an incomplete reading of the story and phenomenon of HIV in our society and in the church and can dull our senses to present reality.

6.4 ‘Things are better now’ as inadequate

In chapter one I described the dominance of this narrative and the good reasons for it as a public health message in the UK context. I also challenged it as too simplistic. In terms of HIV education, it is overly reassuring. Regarding personal encounter, it tends to dismiss the feelings of the person living with HIV, and it can minimise the physical, psychological, social and spiritual challenges that they may face.

The suppression of the virus or an improved CD4 count cannot erase HIV or consign it to the past. Most of my subjects experienced ongoing physical ill health at certain times, and several described periods of mental illness.²⁴⁹ ‘Things are better now’ reinforces the myth that HIV is ‘just a virus’ and fails to appreciate the impact of HIV on social and family relationships.

²⁴⁸ M.S. Copeland (2010, p.100) makes this point in relation to the past history and horrors of slavery, and how memory is essential in pursuit of solidarity: “Solidarity begins in anamnesis—the intentional remembering of the dead, exploited, despised victims of history.” Sharon G. Thornton (2002, pp.132-134) links personal memory to the history and memory of a people, of a community. Solidarity with the community of those who have gone before through remembering, offers an alternative narrative to that which is often imposed upon marginalised and suffering people in order to dominate and control them. Not only for the reason of solidarity with the marginalised of today, the remembering of the past, as in the examples I have given here, remind us of important experience that made us feel fully alive once, and call us back to those experiences and the convictions which arose, and struck us then as of utmost importance; experiences which have formed us and made us who we are; experiences and learning which we should not forget lest their impact be lessened in our lives today.

²⁴⁹ In the previous chapter I have described the serious illnesses that Tiago, Joseph, and Gloria have suffered. In chapter one I have detailed the medical research that indicates higher rates of comorbid conditions in PLWH when compared with the general population. Whether the physical sickness a person suffers can be causally attributed to HIV infection as in the case of Gloria and Joseph, or diagnosed as Aids defining as in Tiago’s case, or not, HIV status will inevitably impact upon the treatment, management and any recovery from other types of sickness. Forms of mental illness often accompany HIV as in Martin’s case.

As Cate puts it, after diagnosis the person cannot but assume a new HIV positive identity which requires continual navigation. HIV is not only a health condition to manage; it is an ontological reality:

*“When you are diagnosed it lands, like a ton of bricks. How do you get up out of that ton of bricks....and make something beautiful from that? And it’s a process and it takes a long time...an ongoing process...a continual process of coming to terms with HIV and new circumstances and new situations, as they present, every day.”*²⁵⁰ (Cate)

Because the ‘just a virus’ myth is so pervasive and subtly persuasive it is important to notice it if one wishes to honour the lived experience of the person. To inquire into what living with HIV in the body of Christ means, a critical consideration of the assumptions implicit in this myth is required. Minimising the impact of HIV can be emotionally protective but is also likely to prevent one from being with, and avoids suffering with, the person living with HIV. I am saying that to consciously suspend even those precious narratives rooted in painful memory, assists the process of listening and openness in the encounter with the person living with HIV, as they are.

6.5 The ‘guilt and innocence’ narrative

The guilt and innocence narrative has much deeper anthropological roots. It has been expressed collectively in Western culture whenever the impulse towards culpability for suffering results in individuals and groups being blamed and persecuted for the ills of society. Historically, scapegoating relies upon identifying those who are perceived to threaten wider society, and is usually justified by way of moral distinctions of innocence and guilt.²⁵¹ The phenomenon of ‘moral panic’ has been documented, not least in response to

²⁵⁰ CAPS: Loades K. (dir.), (2017). Positive Faith. HIV and Faith Matters Series. *As a Christian how do I come to terms with diagnosis?* Available at Positive Faith website and <https://www.youtube.com/watch?v=-je4hgrFF58&list=PLwWBS0fwuez8d-7sWaaQOyWgSf1cgSuHZ&index=2> [Accessed April 2019]

²⁵¹The phenomenon of social scapegoating and persecution in society, and the reasons for it is too vast a subject to address in detail here. The Nazi persecution of the Jewish people in the 20th century is the most obvious example of this collective expression of blame and the evil consequences that follow. Scapegoating happens in response to a perceived or actual threat, including the outbreak of disease. For example, before the horrors of the Shoah in Nazi Germany Jewish people were scapegoated following the outbreak of the Bubonic Plague in the 14th century. 11 Jews were falsely accused of poisoning local wells, put on trial and condemned to death. Thousands of Jewish people lost their lives in the wave of repression and terror that followed across Europe (Giblin, 1995, pp.35-39). This is just one example of how the victimised groups are often the same, and the recurring nature of the scapegoating phenomenon in history.

HIV and Aids (Weeks, 1989a; Lupton, 1994; Washer, 2010). Whenever sex and sexuality have been associated with danger, disease and sin, the moral judgments made create a powerful societal impact (Mort, 2000; Allen, 2002). I believe it important to note this recurring feature in history, in order to be alert to this persistent tendency to attribute blame in response to fears. It appears to be an instinctive human impulse.

The dynamics of guilt and innocence, blame and scapegoating, were and still are evidenced in response to the threat which HIV represents.²⁵² The inherited myth linking sex, disease, sin and punishment, and the affective response it creates is still operative and impacts upon the interpersonal dynamics of any encounter with HIV. It is naïve to think otherwise. The clue that this is so, is to be found in closer attention to the ‘how did you get it’ question.

6.6 ‘How did you get it’ as premature interruption, distracting from presence

Each person interviewed for this thesis mentioned the mode of HIV transmission as a preoccupation for others. ‘How did you get it?’ is often the first question asked when they tell others of their status.²⁵³ It is asked prematurely – that is, before the person living with HIV has arrived at the point where they want or need to reveal the circumstances of infection. When a person shares their HIV status, perhaps in the context of a very personal opening up, where the intention is to share a confidence, or in situations where all that the person wishes to reveal is the fact of a health condition for whatever reason, ‘how did you get it’ interrupts the person in the sharing of their own story.

²⁵²The case of Ryan White the American teenager excluded from school and bullied in the community, only readmitted to education after lengthy court proceedings in the 1980s, is a reminder. So too the case of the first ‘HIV martyr’ in South Africa, Gugu Dlamini, who was kicked, beaten and stoned to death by a group of men in 1998, after she publicly revealed her HIV status. In the mid-1980s the UK government seriously considered incarcerating people living with HIV, and gay men are being criminalised today in many countries in the world. The threat of HIV is often cited as justification. As recently as 2012 on the streets of Athens, women were detained by police in their hundreds, forcibly tested for HIV against their will, and if found to be HIV positive, imprisoned. They were named, and publicly shamed, their personal details and pictures displayed in the media. The justification given by politicians for this official ‘public health strategy’ (during an election year), was the supposed threat to the general population. In particular the threat posed to ‘healthy family men’, by trafficked and other immigrant women working as prostitutes, especially African women. It should be stated explicitly that this claim was spurious, not founded on evidence and seems to have been cynically employed as part of an election campaign which sought to exploit the electorate’s fears of immigration (Weait, 2013). See also Zoe Mavroudi’s documentary film, *Ruins: Chronicle of an HIV Witch-Hunt*.

²⁵³ In particular Gloria spoke at length about this interpersonal dynamic and the need of others to have an answer to the question ‘how did you get it’ which I return to below.

Whenever a personal story is told each detail has a place. The sequence properly belongs to the story teller.²⁵⁴ Unless of course, the one with whom the story is being shared is not interested in the whole story, but rather preoccupied with this or that aspect of the story. When ‘how did you get it’ is asked without this detail first being offered, it’s a bit like saying ‘get to the point that I am really interested in’. Like a badly told joke, where the punch-line is delivered before the set-up, the interruption spoils the story and reveals an inattention to the whole story as the person living with HIV wishes to tell it.

When listening to the personal stories of others, generally their editorial choices are respected. They decide what detail to include and what is omitted. Most people exercise control over what is revealed and what is kept private. It allows us some power over what is known about us and therefore how we are viewed by others. The choice to retain secrets about ourselves is central to one’s sense of privacy. When that is lost a person becomes very vulnerable and potentially open to the exploitation of personal information by others.²⁵⁵ So it is striking that the usual rule of politeness of not prying, not asking intrusive questions, is so noticeable in the frequent breach of that social convention when it come to the experience of people living with HIV. In most cases the insensitivity is unintentional. Rather, unwittingly, the guilt and innocence narrative asserts itself: the impulse towards culpability, and the habitual linking of sex, disease and sin, distracts attention and impatiently requires an answer.

6.7 ‘How’ and ‘why’ – judgment creeps in

Understandably a person diagnosed with HIV wants to know how they were infected. It is as natural an inquiry as questions about how HIV works in the body or how medication can subdue it. Some people will have a fair idea and others will be unsure. Paul knew that his treatment for haemophilia caused his infection. Tiago had been “...*living la vida loco*...” His period of hedonistic clubbing on the London gay scene exposed him to HIV. Rosie had spent

²⁵⁴ I am not suggesting here that when a person living with HIV tells their story to another person it will always be well constructed or formulated, told with a beginning, a middle and an end. As Arthur Frank (2013) observes the structure and manner in which stories of illness unfold vary. It may be delivered in a controlled fashion, or accompanied by tears or sounds of chaos. The narrative structure or lack of structure through which the details of the story unfold also reveal the person. The particular way in which a person shares their story with another, speaks to ‘where they are at’ in relation to living with HIV, and needs also to be respected.

²⁵⁵ For a discussion of theoretical perspectives in regard to HIV and issues of concealment and disclosure see Klitzman & Bayer (2005 pp.5-10).

most of her adult life as a religious sister. Diagnosis confounded her expectations. Her husband tested negative, as did the only other person with whom she had ever had sexual intercourse, a priest back in Africa. Maybe she was infected during a hospital procedure in Africa? She remains unsure to this day. Cate's partner was living with HIV. She remembers the awful moment when the condom broke, introducing fear into their act of love.

Humans seek causal relationships for any event in life. This much seems obvious. Reflecting upon instances where she has been asked how she was infected Gloria identifies the need to assuage a basic human anxiety:

"..human beings still ask that question because we want to have a cause and effect, it somehow makes us feel safer."²⁵⁶

However, 'how did you get it' is a loaded question when it comes to HIV. It appears to be different from 'why?' Ordinarily *how* is of a different order of inquiry to *why*: *How* is a matter of fact; *Why* is a matter of meaning. However, in the context of HIV disclosure they are confused.

How HIV infection occurs may be explained simply: a virus entered the person's body. A person living with HIV will ask both 'how' and 'why' they are infected, but the consideration of 'why' should be at their own pace as they seek to understand their experience. 'Why' requires reflection and may be asked repeatedly without ever being satisfactorily answered.

'How did you get it' triggers a discomforting response in the person living with HIV. With HIV 'how' always implicates 'why', and raises further questions relating to sexuality, sexual behaviour, drug use and the quality of intimate relationships. The person shares the same human impulse to culpability of the inquirer but may not yet have processed their own preoccupation with guilt and innocence:

"Then you start the blame game. It must have been a mistake. It must have been my mistake, I shouldn't have got this....You go through all these emotions, you start to think, oh...How did I get this? Where did I get this? Was it my mistake? All these questions and reflections." (Piramo)

²⁵⁶ Gloria's insight is reflected in research that considers how 'Just World' theory relates to HIV stigma. See for example Anderson (1992).

When asked 'how' the suspicion arises that the person interrupting the story actually wants to know why, (reflecting the person's own process of finding reasons). How someone caught the flu is not asked because it would reveal nothing of use, and certainly not raise matters of a deeply personal nature. But in this context 'how' forces both parties into often painful territory of theological, moral and ethical assessment.

In the hearing of a person living with HIV the question 'how did you get it?' translates as 'what did you do to get it, whose fault was it, are you guilty or innocent?' Although lacking the disciples' directness when they asked Jesus 'who sinned'²⁵⁷ regarding the man born blind, it still aims to find fault and assess guilt or innocence. Thus, blame and judgment are introduced in that moment between the parties. It reveals an unconscious attachment to the guilt and innocence narrative, and fears that the person living with HIV has that they may be judged are justified.

6.8 Insensitive to the complexity of HIV disclosure

To reveal one's HIV status to others, especially soon after diagnosis or before coming to acceptance, is no simple matter. Klitzman and Bayer (2005) offer a compelling series of case studies of different people living with HIV, and conclude that sharing this information with others requires "moral, social, and psychological decision making under conditions of extraordinary stress" (p.12). The dynamics of external and internalised stigma are such that for people living with HIV there are two linked anxieties at play. Lack of understanding and judgment are most feared before any disclosure. This fear meant that Gloria never told her family, and Lazarus kept his status secret lest his landlord evict him. In response to her disclosure, Cate received a long letter from her parents which felt like *"a complete criticism of my life."* (Cate)

'How did you get it' reinforces this anxiety because in the asking, the listener reveals a lack of understanding of the complex challenges and considerations before any disclosure is made, and the emotional preparation required. The person with HIV may still be processing questions of trust, or feelings of anger or betrayal by a partner or parent. Where feelings of guilt have been internalised and are unresolved, they are unlikely to be ready or want to

²⁵⁷ John 9:2

‘confess’ any shame they feel. It is not realised that in asking ‘how did you get it’ the person with HIV is being asked “..to bear one’s soul...one does that in the confessional, but otherwise one does not go and bear one’s soul or one’s experience with others.” (Gloria)

The question invites disclosure of very intimate detail and raises difficult questions that the person may still be wrestling with. There are so many possible answers beyond the examples from Cate, Tiago, Paul or Rosie given above. ‘How’ may be asking the person to reveal that they were raped or that their father abused them. It may require them to reveal details about the state of their parent’s marriage, or their own relationship difficulties.

To say the words ‘I am HIV positive’ requires courage, because these words name a hard reality. ‘How did you get it’ asks more than how the virus in the blood got there. Such an apparently simple question, places the onus in a burdensome way on the person living with HIV, to explain themselves further. It asks that they revisit any internalised guilt and expose wounded feelings. It asks that they risk the possibility of being judged regarding aspects of their life which they may wish to remain private. It requires that they bring to speech what may be very painful or considered shameful. Asking ‘how did you get it’ without serious thought as to why one needs to know, is insensitive and obstructive to any encounter with a person living with HIV.

6.9 The personal challenge of suspending narratives

As with all my interviewees, narratives provide a sense of place in the journey of a person’s life. They map the past, and make claims about the emotional, psychological and spiritual state that the person embodies now. Stories shared convey what matters to a person and construct a social identity by which they seek to be known.²⁵⁸ They provide a personal meaning-map for life comprised of milestones, signposts and anchors all at once.

They can be difficult to let go or suspend because without them one feels vulnerable. Often the most powerful narratives are those that are most hidden, like the ‘just a virus’ and ‘guilt and innocence’ narratives. However, as I hope to have shown, narratives often carry assumptions and prejudices into relationships that create barriers between people.

²⁵⁸I hope that this is apparent already for example in the short quote from Cate above, and the examples given from the theologians above, as well as the evidence in chapters 3 and 4.

The self-conscious reflective attentiveness required to notice them, and the willingness to become vulnerable is a first move towards understanding the experience of an HIV diagnosis, or that of any major illness. To risk the destabilising impact on one's own meaning-map is also an empathic act, and a step in the direction of place sharing, because as Arthur Frank has observed: "Serious illness is a loss of the destination and map that had previously guided the ill person's life: ill people have to learn to think differently." (2013, p.1). Vulnerable openness then, can also be viewed as a gesture of solidarity with the person whose meaning-map of life has been so disrupted by an HIV diagnosis. In Christian and theological terms this choice indicates an intentional preparation for and a stance of openness to the encounter with Christ living with HIV at a site of vulnerable suffering.

6.10 Summary

My intention here has been to draw attention to two complex narratives attached to HIV: the first 'just a virus' misinforms people through reassuring but inaccurate 'facts' about HIV; the second - 'guilt and innocence' – often exposed in a preoccupation with the mode of transmission, is constructed of usually unconscious but long-held and deep-seated fears and prejudices around sex, disease, sin and punishment. As Vincent Leclercq (2010 p.21) argues the authentic question from a Christian perspective is not 'how did you get it' but 'how did you get through it'. Both narratives, especially when unconsciously held, are obstacles to any encounter with HIV. That they produce pastorally insensitive responses which create added suffering for the person living with HIV is sufficient reason to notice them. As distortions they inhibit the fullest possible understanding of what HIV is and what living with HIV might mean. And, they serve as a barrier between oneself and the encounter with Christ who wishes to be seen and heard, embodied in the person who is infected or directly affected.

Chapter 7. The way of the passion of HIV

7.1 Denial and resistance in the garden of Gethsemane

To further support my argument and understand what HIV in the body of Christ is like, I begin by sharing the place where the trauma of an HIV diagnosis is lived through as a type of gethsemane experience.

In the stories here, prior to HIV testing, a kind of complacency related to denial is evident. Francis squeezed his clinic test into his working day lunch break, as though this was just another task to tick off his 'to do' list. He was not at all prepared for a positive result. Had he thought through the implications, he would surely not have scheduled an important meeting for the same afternoon, much less a date with his new boyfriend that evening. Joseph recalls there were some tell-tale signs that his immune system was damaged - persistent tiredness, gum infections and a fungal infection that was slow to heal – but *"unconsciously"* he was *"avoiding being tested."* A friend who was with Martin during the period of seroconversion took him to the hospital where he would be tested:

"I think he had a suspicion of what was happening" but "I was too ill to understand what I was doing." (Martin)

Paul had seen reports on television and read stories in the papers about children with haemophilia who had been infected with HIV. He remembers how they were portrayed as *"the innocent victims who hadn't done anything wrong."* Even as he read about these children, being treated at the very hospital he attended, he had no clue the stories referred to him:

"I remember thinking at the time, y'know, blimey, they must have to be ferried in, in dark cars with dark windows. And I didn't realise that was me." (Paul)

For Rosie the news came during her first pregnancy. For most of her adult life she had lived as a religious sister. HIV infection was not what she was expecting. Her diagnosis and the subsequent miscarriage of her child sent Rosie into *"a time of crisis [which] lasted for years."*

By contrast, Tiago was worried he may be infected. He had been engaging in high risk behaviours, but he too was unprepared:

“At that time I was living the ‘la vida loco’. Trying out London. Vauxhall style life. A lot of clubbing, drugs and sex. [The test results] destroyed me. I cried, from Waterloo to Vauxhall, and all the way and under the rain. It was, it was the worst news I could have.” (Tiago)

Cate and Lazarus also knew that they had been exposed to HIV in the relationship with their respective partners. But the diagnosis still came as a shock: *“Like a ton of bricks”* for Cate. Lazarus found it hard to believe because he felt so strong and healthy. He knew people living with HIV and had witnessed many more die from Aids back home in Zimbabwe. He remembers visiting a friend with Aids previously. The man was so weak and frail that Lazarus had to wear protective clothing and a mask before entering the hospital room. He felt sure that the doctors had made a mistake, but his test results in 2002 constituted an Aids diagnosis:

“At the time of diagnosis my CD4 count was extremely low, and the viral load was way up. The doctors were really quite surprised...It was shock. Quite shocked. Because, eh, from the explanation that I got, I was like, more, more, more than walking wounded, because I was very close to just, going down like that.” (Lazarus)

Lazarus felt healthy, but it began to sink in. With a long sigh of breath out he tells me:

“I, I, I, I was scared, to say the least, because the experience that I had, of all the people that I knew diagnosed HIV, most of them had died, yes. So my thought was, my God how long am I going to survive for.” (Lazarus)

In the Gospels when Jesus made His way with the disciples to the garden of Gethsemane to prepare for what seemed inevitable, He anticipated what He would face in the coming hours.²⁵⁹ His years of public ministry, and conflicts with the religious and civil authorities were reaching a crisis point. Jesus’ mission in life, in accordance with the will of God His father, had led Him to this place. He foretold His coming trial and death and told the disciples that it must be so. When Peter protested, Jesus rebuked him in the strongest of

²⁵⁹ In the Gospels of Mark and Matthew Jesus predicts His Passion and death on three occasions: Mk. 8:31-33; 9:31; 10:32-34; Matt 16:21-23; 17:22-23; 20:17-19. Similar predictions are also found in Luke 9:22; 44; 18:31-33. For a discussion of scholarly opinion as to the extent of Jesus’ foreknowledge of His Passion and death see Brown, 2010, pp.1468-1491.

terms, 'get behind me Satan!' ²⁶⁰ Jesus appears to have prepared himself, and as I will show later, He was also concerned to warn His friends of the shocking events to come. ²⁶¹

For my subjects diagnosis was unprepared for and unexpected, because it was so feared:

"..to this day, it is still the most bewildering day of my life, really, because I wasn't expecting it" says Francis. Even where reason to anticipate a positive test result exists, the outcome is shocking. Despite circumstances where one might calculate the risk of exposure to be high, as with Cate, Tiago, Lazarus and Paul, there is a part of human nature which prefers to deny that HIV can claim a place in our bodies, in our lives. This more or less strong tendency to deny the possibility that one can be infected by HIV is the pre-condition which ensures that an HIV diagnosis is so disturbing.

The same tendency to denial is evidenced in the wider community when myths about HIV and practices of exclusion are used to provide a veneer of protection to the social body. It is also another motivation for the 'How did you get it' question, because individually, it is emotionally reassuring. It is the same basic strategy of denial mentioned above. Employed subconsciously, it maintains distance between ourselves and that which - or the person who - arouses deep seated fears in us. This is apparent in the stories of each of the people I interviewed. The rational knowledge of HIV infection as theoretically possible was present, but the full implications and the attendant anxiety are kept at bay as long as HIV can be thought of as something that only affects others who are not like us. Denial is used in anticipatory resistance to the possibility of HIV infection. This capacity for hidden layers of denial only becomes fully apparent after the fact: when one is confronted by that which is most fearful without the possibility of escape. Andrew Sullivan (1999, p.29) sums up his contrast time before and after HIV diagnosis: "I walked into my doctor's office and my life

²⁶⁰ Mk.8:33; Matt.16:23

²⁶¹ For the purposes of this study I am taking the Gospel according to Mark as foundational and the synoptics as most pastorally useful in this context. The Gospel accounts vary in terms of the Christology they present. John presents Jesus as certain about what he must do; unaffected by doubt, and certainly not afflicted by distress or anxiety. His portrayal of Jesus contrasts markedly with those of Mark and Matthew. For the purposes of this thesis I find the emphasis in Mark and Matthew on the humanity of Jesus of most relevance, as I relate my subjects experience not only to that of the disciples, but also to the human experience that Jesus underwent. However, I will not restrict myself or the reader to the synoptic accounts and will refer to John's account when it serves the purpose of this thesis.

was changed for good. The news of my HIV infection was the last thing I expected, and the first thing I feared.”

An HIV diagnosis interrupts life and incurs losses of health, probably relationships, and hopes for the future. Whatever meaning-map a person holds, the narratives of past, present and future that anchored them before, are thrown into turmoil. Each of my interviewees experienced a state of intense emotional distress after diagnosis. Suddenly they found themselves in this place of fearful confusion, forced to confront a new hard reality that cannot be denied. A reality so feared it was too difficult to imagine. Literally inconceivable until unavoidably real.

Incomprehension and shock is clear in Francis’ recollection of that day:

“I just rang work and told them just that I was really ill, I’m sick and I can’t come in, and that was it, the whole day was just a bit of a blur. The whole thing was, it was just sickening...if someone had said do you want to put all your money on what the results of this test would be I would have never have said I was positive.” (Francis)

When presented with the facts, Lazarus sought alternative explanations, contraindications that might change the situation. The tendency to deny the hard reality is persistent. As with Paul ‘it can’t be’ is preferred until protest is exhausted.

As noted above the apostle Peter had insisted ‘it can’t be’ when Jesus’ predicted His impending Passion and death. Peter continued to insist ‘it can’t be’ when he drew his sword against the crowd that came to arrest Jesus.²⁶² Previously he had named Jesus as the awaited Saviour²⁶³ but Peter and the disciples did not understand the implications of Jesus’ predictions or what this would mean.²⁶⁴ From the Gospel accounts it is clear that whatever ending to the story they had imagined it was not this.²⁶⁵ They were not prepared for the shocking events of their Gethsemane night. Despite Jesus’ requests that the disciples stay

²⁶² John 18:10. Only John names Peter but the incident is recounted also in Matt.26:51, Mk.14:47 & Lk.22:50

²⁶³ Matt.16:16; Mk.8:29

²⁶⁴ Jesus makes it clear that Peter misunderstands in His rebuke to him in Mk.8:33; Mt.16:23. Luke 9:44, & 18:31-33 emphasises the disciples lack of understanding also noted in Mk.9:32

²⁶⁵ In Mt.20:20-28 & Mk.10:35-45 the disciples James and John cause indignation amongst the disciples when they discuss their positions of importance in the awaited new kingdom that they imagine Jesus will eventually rule over.

awake Mark tells us that they could not,²⁶⁶ and Luke describes this as a kind of emotional exhaustion because of the grief they feel.²⁶⁷ Like my interviewees, in the garden of Gethsemane, the disciples also resisted a hard reality that they were unprepared for and did not want to accept.

Notwithstanding having predicted his Passion, the realisation of the trials to come and the death sentence to follow hit Jesus hard too, as He prayed at Gethsemane.²⁶⁸ In his humanity He wrestled with the full implications of it all. Luke tells us that His agony was such that the sweat dripped from him like drops of blood to the ground.²⁶⁹ Henri Nouwen (2006, p.40) comments that in those moments “Jesus couldn’t face it. Too much pain to hold, too much suffering to embrace, too much agony to live through.” He was surely feeling overwhelmed. Jesus was shattered (Harrington, 2010, p.101).

The fraught plea of Jesus to God His father that ‘the hour might pass and this cup be taken away’²⁷⁰ reflects the desperation felt when the phrase ‘HIV positive’ can no longer be avoided. When Tiago knew that HIV was in the very sweat and tears that dropped from his body and mingled with the rain. When it hit Cate “*..like a ton of bricks*” or Paul, “*..like a bomb that hit the ground and didn’t go off straight away*” but “*altered everything.*”

Contemplating his ‘hour’ and ‘cup of suffering’: the impending torture, and the Cross that He would carry to his own crucifixion Jesus was deeply distressed. “My soul is overwhelmed with sorrow to the point of death” He tells the disciples.²⁷¹ The accounts of Mark and Matthew describe something akin to a break-down. It is the only time that Jesus is described in such a state.²⁷² I intend to be explicit: at Gethsemane Jesus was confronted by a pain-full

²⁶⁶ Mk.14:40

²⁶⁷ Lk.22:25

²⁶⁸ See footnote 259 regarding the foreknowledge of Jesus. In this study I have relied upon the scriptural scholarship of Raymond E. Brown (1928-1998), Catholic priest and Professor Emeritus at the Protestant Union Theological Seminary, New York; supplemented by the work of Wilfrid J. Harrington, OP, Professor Emeritus, Milltown institute, Dublin; Marcus J. Borg (1942-2015), American New Testament scholar and theologian, and John Dominic Crossan, Irish-American New Testament scholar and historian, both members of ‘The Jesus Seminar’; and American Episcopalian priest Fleming Rutledge.

²⁶⁹ Lk.22:44

²⁷⁰ Mk.14:35-36; Mt.26:39-44

²⁷¹ Mk.14:34; Mt.26:38

²⁷² Fleming Rutledge (2017, p.374) notes that Mark presents the emotions that Jesus felt at this time unflinchingly. Raymond E. Brown (2008, p.153) translates the greek word *ekthambeisthai* used by Mark to describe the emotional state of Jesus as “to be greatly distraught” and elaborates “a profound disarray, expressed physically before a terrifying event: a shuddering horror.”

reality, so forceful, that He appears to have felt spiritually and mentally assaulted, in a way that was also physically exhausting. This is surely descriptive of that kind of intense experience in life when a person feels that they simply cannot go on.

As the reality of an HIV diagnosis begins to hit home, and can no longer be avoided, each of my subjects encountered a new painful reality, as the disciples did. Like Jesus they felt overwhelmed by the prospect of trials to follow. After the manner of Jesus, Cate turned to God in anguished prayer:

“I started crying, and this sound came out of me like a wounded animal...I remember rocking, and crying, from somewhere deep in my soul...‘out of the depths I cry to thee, Oh Lord’, a really deep, soul cry.” (Cate)

Cate experienced the anguish of her own gethsemane.

7.2 Trusting God in dire circumstances

The Passion of Jesus began in anguish as He struggled with a hard reality and questioned whether it must be so. Jesus qualified His distraught plea that if possible, this cup of suffering be taken from Him, with submission to God’s will: ‘Not what I want but what you will’ in Mark; ‘your will be done’ in Matthew and Luke.²⁷³ By the time the arrest party approached, Jesus’ determination seems renewed. Something happened within Him as He prayed. Luke gives the only explanation, saying that an angel appeared to strengthen Him.²⁷⁴ Jesus was ready to pick up His Cross. Borg and Crossan (2008, p.123) emphasise that this does not reflect “..a fatalistic resignation to the will of God, but a trusting in God in the midst of the most dire of circumstances.”

Jesus had told the disciples that to follow him would mean being willing to pick up their own cross when the time came²⁷⁵ and strengthened, Jesus enacted this teaching by example. He had come to a point of acceptance.²⁷⁶ The disciples had not yet understood and far from accepting what was happening, they fled Gethsemane and abandoned Jesus.²⁷⁷ In any case

²⁷³ Mk.14:36; Mt.26:42; Lk.22:42

²⁷⁴ Lk.22:43

²⁷⁵ Mk.8:34; Mt.16:24; Lk.9:23

²⁷⁶ As he is being arrested Jesus speaks of the necessity of all that is happening so that the Scriptures are fulfilled: Mt.26:54,56; Mk.14:49

²⁷⁷ Mt.26:56; Mk.14:50-52

the Cross that awaited Jesus was His alone. Jesus had predicted that they would face their own trial experiences later.²⁷⁸

Again, shock, resistance and denial attended diagnosis for each of my interviewees. To accept HIV, this unwanted fact of life, took more than a few hours prayer. The gethsemane experience lasts longer than one night. This cup of suffering will be felt through many hours of questions, doubts and protest. Like the disciples there will be times when escape seems the only option. At other times fears recede, forgotten in exhausted sleep perhaps, but for our subjects the 'hour of suffering' will be lived through weeks, months, even years.

Disorientated, this life-shock challenged their faith and belief in God. The question then, becomes one of willingness to trust God, in this new dire circumstance. And, whilst trust in God is fundamental to Christian faith, and strengthening necessary if one is to pick up one's own cross, it is no foregone conclusion.

7.3 First glimpses of the scandal of the cross - Between gethsemane and crucifixion

The distress of their leader and teacher, followed by His arrest surely shocked the disciples. Like the experience of HIV diagnosis, their experience at Gethsemane was characterised by shock. In what follows I argue that it is the scandal of the Cross, and all that this means, that provokes this response. At Gethsemane the Cross comes into view. The terror of it becomes real for the first time. By listening to the experience of my interviewees further through the lens of the Passion of Christ I will show that the meaning attached to this scandal is multi-dimensional. We will see that for those subjected to it, the scandal of the Cross is profoundly affective and disturbing, and the awareness or sense of being scandalised has many layers.

After their last supper together, before they arrived at Gethsemane, Jesus had warned the disciples that they would fail Him at Gethsemane.²⁷⁹ In Mark and Matthew His prediction that they will abandon Him comes at the same point that Jesus predicts Peter's threefold denial.²⁸⁰ Peter was vehement in response, he would rather die for Jesus before he would deny Him, and the disciples all said the same!²⁸¹ Peter sounds as certain of this as Jesus did

²⁷⁸ Mk.13:9-13; Mt.17-21; Lk.12:11-12

²⁷⁹ Mk.14:27; Mt.26:31

²⁸⁰ Mk.14:30; Mt.26:34

²⁸¹ Mk.14:31; Mt.26:35

when He predicted his own arrest, trial and death. Peter would not lose faith in Jesus even if everyone else did!²⁸² As we know Peter and the disciples were overcome by grief, fear and confusion. By the end of the scene at Gethsemane, the ‘all’ who said the same, had all abandoned Jesus.²⁸³

This failure on the part of the disciples, to which Jesus refers, is something other than just *their* betrayal of him in his hour of need. I will come back to this point shortly.

As Jesus and the disciples approach Gethsemane, the NIV translation has Jesus warn them: “This very night you will all fall away”.²⁸⁴ It is possible to hear this as Jesus admonishing the disciples, and in turn, for anyone who hears this scripture today to apply it introspectively. This interpretation, which I have often heard used in preaching and teaching, invites the listener to put themselves in the place of the disciples whose failure adds to Jesus’ suffering, and in turn, consider the ways in which they also fail to remain faithful to Christ and His teaching in daily life. There is within Christian tradition a way of reflecting upon and preaching about the Passion of Christ which emphasises how each sinful act is a kind of betrayal of Christ. Metaphors of sin as ‘a thorn in His crown’ or as ‘piercing His side’ have been used to emphasise individual sinfulness. As a pedagogical process of theological imagination, reflection upon Scripture in this way takes us from a focus on the person of Jesus and moves quickly to a focus on oneself. This emphasis, I suggest, encourages the listener to dwell less upon the Passion of Christ as the greatest sign of God’s love for us,²⁸⁵ and more upon those ways in which one has ‘fallen away’ from Christ, as the disciples ‘fell away’ from Jesus in His time of need. This is an aspect of the ecclesiological culture within which my interviewees were formed. In their stories a keen awareness of sin is evident. I want to notice how the awareness of personal sin often received in childhood, formed an understanding of the human divine relationship, and how remaining faithful to Christ is often equated with and understood in terms of, obedience to Church teaching.

²⁸² Mk.14:29; Mt.26:33

²⁸³ Mk.14:50; Mt.26:56

²⁸⁴ Mk.14:27; Mt.26:31

²⁸⁵ St. Paul of the Cross (1694-1775) founder of the Congregation of the Passion, understood the Passion of Christ as the most overwhelming sign of God’s Love for us. (Spencer, P. F., 1994, p.11).

As a child Paul remembers feeling saddened by the suffering in the world and wondered how different things might have been if Adam and Eve had *"...not taken the bite out of that apple."* Martin remembers how this focus on individual sinfulness, and by contrast the potential for holiness, was conflated with obedience to the Church:

"Do what the Church tells you to do. What the Church says is morally right or wrong is what is morally right or wrong. What you think, it's got nothing to do with what you think. What you think is wrong. And how you act or how you behave is wrong, everything is wrong, I have no say in it, I am just this sinner who acts badly and is full of guilt and shame and remorse, and I can go to confession and I can be forgiven, and be good hopefully for an hour or two and then it can start all over again. Yes. That everything I do was selfish and sinful and that is how it was. And it seemed to me that that was what everyone believed, it wasn't just a childlike view of things it was the adult's view of how things were also." (Martin)

Similarly, Joseph remembers how he was taught that Christian life was measured by one's adherence to Church law:

"..a lot of the Catholic culture is about rules, regulations, and doing things that should be done or avoiding things that should not be done. There are too many rules and regulations, people are focusing more on the letter of the law and forgetting the spirit of the law, there is too much of that.." (Joseph)

More positively, Tiago is still inspired by the call to personal holiness that he learned in his parish growing up, as emphasized within 'Opus Dei' spirituality. As a child this required frequent confession and self-examination. During his time in the seminary he would wear uncomfortable garments under his regular clothes, or a cilice (a spiked garter), as an act of mortification of the flesh. He had learned that personal sanctity would require that he subdue his body and dangerous desires, especially those that lead to 'impure thoughts' and sexual sin.

For Francis, *"..being so saturated.."* in stories of the lives of the saints as a child, developed his interest as a teenager in mysticism. Francis of Assisi and Padre Pio were his heroes. Accompanied by *"..quite extreme examples of renunciation and asceticism.."* he became convinced of the power of faith, to transform a person's life. However, his aspiration to live

like these “..olympic spiritual athletes..”, was tempered by humility. He laughs when he tells me that he never thought he could obtain parity with them:

“..you are always aware that, Oh my God, there is no way that I’m in that league because I am petty and I am greedy.” (Francis)

I want to notice how the desire to imitate and follow Christ and the holiness of the saints are, practically speaking, contrasted with individual sinfulness. To be faithful to Christ is aspired to, but personal sanctity is thought unattainable because of personal sinfulness. That comes across in Martin’s words. Francis’ had simultaneously interiorized both the call to sanctity and the impossibility of attaining it. In his words, the example of those saints who became, “..transmogrified individuals because their faith was so at the core of what they did..”²⁸⁶ serves, by way of comparison, to emphasise the individual failure to live holy lives. This faith-stance impacted my subjects’ understanding of HIV diagnosis which will become clear.²⁸⁷ For now, I want to notice that an emphasis on or preoccupation with individual sin, was a formative religious-cultural influence in the lives of most of my subjects.²⁸⁸

²⁸⁶ Transmogrified: Transformed in a surprising or magical manner.

²⁸⁷ Below I show that a preoccupation with personal sin is often internalised as part of the guilt and innocence narrative and leads to consideration of HIV as a punishment from God.

²⁸⁸ There is another version of the way in which this understanding of the human-divine relationship is conveyed to children, to the same effect. On a Positive Catholics retreat, I was in the company of a father whilst he collected his son from our childcare team. I heard him ask his son what the boy had been up to in the previous hour and whether or not he had behaved himself well: ‘And remember’ the father said, ‘you must tell me the truth because even if I do not know, God knows everything. He is watching you and knows what you did and whether you tell the truth or tell a lie’. This was said most gently and kindly by the father. This man had suffered from the effects of a late HIV diagnosis. The virus had disabled him and he could barely walk, and his mind was disturbed and his brain impaired by the virus which had crossed the barrier between brain and body, so that he suffered with HIV associated dementia. He was found wandering the streets of London after several days absence from the family home, and that is how he came to be diagnosed. The shock to his family was great and his ill health, including a change in personality had a serious impact upon his marriage. I was aware that this 6yr old boy had also lived through all of this with his father and alongside his mother, and he had observed it all. He was a remarkable boy whose love for his parents and his desire to please was evident in his behaviour. He had already developed a reputation for being comical amongst the retreat group, and I know from his parents that this was a strategy that the boy had employed to ‘lighten the mood’ within the family when he witnessed the suffering of his mother and father. At least he might make them laugh and the tears might stop. My heart ached when I listened and I begged the father, quietly beyond the boy’s hearing, not to plant this idea of God as a kind of spying policeman figure into his child’s head: ‘Please do not say that to your boy’ I pleaded. I ‘congratulated’ the father on the evident kindness and joyful nature of his child. I suggested that his boy would be better served by understanding how much God loved him and supported the whole family in every circumstance. Without meaning to, the father was implying that our God’s love was conditional on the child’s behaviour. He was using belief in God to control his child in a way that could distort the boy’s understanding of the divine-human relationship, and planting the seeds of this double-bind spirituality within

This habitual focus on sinful human nature rather than upon the person of Jesus, may result in missing an alternative reading of Jesus' prediction of the disciples' failure, which I suggest offers a more helpful understanding of what it means to undergo a gethsemane experience similar to that of Jesus' first followers. The passage does speak of the disciple's frailty and human weakness of course. According to Raymond Brown (2008, p.141) and others, in Mark's gospel especially, the shortcomings of the disciples are presented unapologetically, so that those first Christians who heard this account would be encouraged in their faith, despite any denial or failures that they may have experienced in their own lives (Borg & Crossan, 2008, pp. 91-107, 113; Harrington, 2013, pp. 108-118). Those first followers of Jesus faced hostility from within their own communities and pressure from the state and religious authorities to deny their faith in a way that we in Western society do not today. It was a matter of life and death for some of them as it was for Stephen, who was stoned to death for his refusal to deny Christ.²⁸⁹ Mark wished to show that if the disciples and Peter, the first amongst the apostles, were capable of failure, then such failures are not the end of the story. Mark wished to encourage those early Christians to persist in faith despite grave danger. He is "...offering a pedagogy of hope based on the initial failure of the most famous followers of Jesus and a second chance for them." (Brown, 2008, p.141).

However more important for my argument is to hear Jesus' warning as demonstrating His care and concern for His friends. Despite His own awareness of the fate that He was to suffer, alone, Jesus still had the presence of mind and love for His followers to warn them as a friend warns another of danger. He was warning them that a moral crisis would come. Jesus knew and understood them. His emphasis was not on the fact that they would let Him down, but that they would feel dramatically and profoundly let down by Him (Brown, 2008, pp. 127, 133). They were about to face a serious crisis for which they were unprepared and during which their faith in Him and trust in God would be tested. Each person in this study experienced a similar crisis and the question of being radically, profoundly let down by God, arose for each of them.

which God sets unattainable standards for us to meet, and when we fail to do so, the risk that God's love will be withdrawn. One should always step lightly in offering advice to parents on their nurturing of their children. Fortunately, the father took what I said in friendship, and I think he understood.

²⁸⁹ Acts 7:54-60

As with each of those interviewed, Martin had understood his life as guided by Christ. In common with Rosie, Tiago, and Joseph this had led him to commit to formal 'religious life'. In his case, four years in the seminary. For him, God was someone who kept him safe. He describes this feeling of being let down most explicitly:

"I believed in a God that was actively involved in my life, who had led me to a point, or led me to believe that my life would go in one direction...then that same God had taken me in a completely different direction which now included living with HIV. So, it made me question what kind of God is this, what kind of God would play these kind of tricks, or what could be the meaning of this, what could be the point of it? What have I done to deserve this?...I found myself...in a totally emotionally unsafe place again. So things had got worse not better, and this God that I believed in that would make everything right I thought, what is he doing? Where is He taking me to? I wanted to let go of God, I wanted to say I'm done with you! I almost wanted to say I don't believe in God, there can't be a God." (Martin)

Like the disciples and each of the people in this study, Martin had sought to follow Christ and live his life in accordance with God's will just as Jesus had. Now, in the gethsemane of diagnosis his expectations were confounded and his faith tested. The terrifying confusion of gethsemane challenged the whole meaning of Martin's life and his understanding of relationship with God. The fear and disorientation, the disruption to his world-faith-view so great that he contemplated suicide as he considered the possibility that the God in whom he trusted, was not. The gethsemane experience inevitably "...evokes the experience of being forsaken by God" (Söelle, 1984, p.85). There is the feeling of being let down, betrayed and abandoned by Christ.

7.4 Further glimpses – the affliction of scandal

Simone Weil (2009, pp. 67-82) usefully distinguishes between degrees and types of suffering and makes the point that not all pain has the lasting effect that more intense suffering causes. For example, a toothache is painful, but once the infection is treated or the tooth removed the suffering ceases. One can recall the fact of having suffered, but the nature of the suffering has no lasting effect other than as an intellectual memory. It makes no lasting

impact and does not affect the sense of self. Physical pain alone “leaves no trace in the soul” (Weil, 2009, p.68).²⁹⁰

Above I referred to living with HIV as an ontological shift. The initial suffering that attends diagnosis changes a person in aspects of identity, relationality and meaning to such a degree that the suffering itself is never forgotten in the way that temporary pain is. Suffering stays with the person, literally re-membered in mind and body. It is re-membered in social contexts for the rest of the person’s life, not least because the virus in the body never goes away. The complexity of disclosure, also discussed above, ensures that HIV is always re-membered and present, whether spoken or in silence, in the wider social body(s) to which the person belongs. The potential for and re-membered consequences of painful experience remain actually present whenever a person living with HIV is with others, be that in bed with a lover, in a bar full of strangers, at the family table, in the convent, the workplace, or the church. HIV is re-membered in the person, never not-known by them even when hidden from others. It is ever present.

Without repeating the myth that HIV is invariably ‘manageable’, it is true to say that the virus and the psychological, social and spiritual implications of living with HIV may only be managed, never ignored, after diagnosis. How HIV is managed (and this may not be within the person’s control), will either increase or decrease proximity to the original-foundational trauma of diagnosis. Although physiological health or illness will have an obvious impact, the ability the person has to resolve the psycho-spiritual and social tensions and conflicts that arise post diagnosis, will determine whether or not and for how long they continue to experience living with HIV as a state of ongoing and more or less severe suffering. The person may have periods of time ‘in remission’ from suffering and dis-ease, but the impact of HIV remains. Post diagnosis, life can only ever be navigated with HIV, as surely as the captain of a sailboat must take into account sails and rudder, whatever conditions at sea prevail.

Previously I argued at some length that HIV is not ‘just a virus’ like any other. I have also defined the gethsemane experience as one in which a fearful reality can no longer be avoided. In Weil’s terms (2009, p.68) the experience of HIV qualifies as ‘affliction’, within

²⁹⁰ Simone Weil (1909-1943) was a French Jewish philosopher, mystic and political activist.

which the psychological, physical and social dimensions of suffering are combined, and because “affliction compels us to recognise as real what we do not think possible” (2002, p.81). Affliction takes a person beyond suffering that does not include these three dimensions, and can never be forgotten. It is the suffering of Job or Tobit and Sarah.²⁹¹ Affliction is what Christ endured in His Passion experience from Gethsemane to crucifixion. To Weil’s categorisation I have explicitly added spiritual suffering.²⁹² Specifically that crisis which arises, as it did for the disciples, because their faith in Jesus the saviour and by extension in God, was severely tested. Affliction, for the Christian, includes a spiritual dimension and “makes God appear to be absent for a time, more absent than a dead man, more absent than light in the utter darkness of a cell. A kind of horror submerges the whole soul” (Weil, 2009 p.70). For any mature Christian, discerning meaning in affliction necessarily invites consideration of the Cross. Under affliction the understanding of Jesus’ challenge ‘to pick up the cross and follow Him’ will be most keenly tested, and faith in Him contested. But how is it possible to follow Christ who seems absent? To explore this further in the context of what it is to be a Christian living with HIV I want to return to Jesus’ warning of the disciples’ failure.

The key phrase used by Jesus in Mark 14:27 and Matthew 26:31 is variously translated as “fall away”; “become deserters”; “be offended”; “have your faith in me shaken”.²⁹³ Brown uses the word ‘scandal’ to more accurately translate what Jesus is describing:

“And Jesus says to them that: ‘You will all be scandalized.’” (Brown, 2008 p.117).

²⁹¹ The reference to Job and Tobit is to the religiously observant men in the Old Testament who were afflicted spiritually, physically, materially and socially, in a total reversal of their fortunes. Sarah is the upright young woman, also in the book of Tobit, whose seven husbands died before any consummation of marriage could take place, subjecting her family to the ridicule and social stigma of neighbours. The stigma and public shame that Sarah’s family endured is of particular relevance insofar as she was ridiculed for failures connected with her sexuality and the reputation she acquired because of the mortal danger she posed to any man who would wish to marry and therefore have sexual intercourse with her.

²⁹² I name spiritual affliction at this point because Weil omits naming spiritual suffering as a distinct category in her three aspects of affliction. I am not suggesting that I am adding spiritual suffering to her account. Her treatment of affliction is thoroughly explored theologically as a spiritual experience.

²⁹³ Respectively NJB & NIV; NRSV; KJV; CSB. The Aramaic Bible in Plain English uses the phrase ‘you will be ashamed of me this night’ in Mark. The notes in the CSB refer to the literal translation ‘will be scandalized in me’. In his 2004 NT translation Nicholas King (2006) uses ‘you will all be led into sin’ in Mark, and ‘You will all be caused to stumble [or: be scandalised] [sic] because of me tonight’ in Matthew.

Brown (2008, pp. 127, 133) agrees that to be scandalized in this context does include notions of stumbling, falling and sinning, but insists that it connotes a loss of faith, especially in the face of tribulation or persecution. The disciples will be scandalized not just by shocking events, but by Jesus Himself. Jesus will be the person who offends them. Their loss of faith will be centred on Jesus and they will feel ashamed of Him.²⁹⁴ In turn, Jesus tells them, they will 'scatter'.²⁹⁵ They will experience dis-integration of meaning, relationship and community. Their faith in Jesus will be smashed as they are separated from Him and each other.

At Gethsemane, the disciples were just beginning to glimpse the reality of the scandal of the Cross. However, it is not only the horror of Jesus crucified and God absent which is scandal enough, it is a horror that comes from the dawning realisation of being viewed by others as someone who represents scandal. So too, for any Christian diagnosed with HIV the scandal of the cross encroaches in a more profoundly disturbing way.

7.5 The scandalising cross in public view

It takes some leap of modern imagination to bring back to mind just how shaming crucifixion was. The cross or crucifix hangs in churches and other public settings. Rowan Williams (2017, p.3) suggests that it might be better appreciated as a sign of humiliation, disgrace and suffering if instead of a cross an electric chair or a guillotine was the image that greeted those who entered a church. People place this symbol of torture around their necks, often without thought as decoration, or more deliberately as a statement of identity. The cross has become a familiar symbol of religiosity and respectability, so that one might forget how shocking and disgusting the symbol of crucifixion once was. As Fleming Rutledge (2017, p.3) has put it "...we can scarcely imagine it as an object of shame and scandal unless it is burned on someone's lawn."

In Roman and Jewish society, the very idea of crucifixion was utterly obscene, usually reserved for slaves and the most serious and despised of all criminals (Hengel, 1977, p.87). It

²⁹⁴ That Jesus is portrayed as suffering anguish at all, as He contemplated His fate at Gethsemane is also a source of scandal. Not only for the disciples but for those who would hear this gospel account later. The divinity of Christ and the Greco-Roman ideal of the calm and emotionally controlled acceptance of death are both disturbed by the image in Mark and Matthew of Jesus distraught and troubled pleading with God to deliver him (Brown, 2008, pp.217-218).

²⁹⁵ Mk.14:27; Mt.26:31.

was *the* most shameful death a person could suffer. Beyond the agony of hanging for hours or days struggling against asphyxiation, or the physical pain of nails driven through the body, shame was what it most terrifyingly conveyed. Crucifixion was not just a painful bodily death it was the final act in a shameful life. The crucified person's suffering was intensified by this absolute humiliation and indignity even in death. More than death alone, it was the prospect of such public shame that struck terror into any who witnessed it and made crucifixion the most effective form of state execution (Hengel, 1977). Other than HIV diagnosis, the only thing that I can think of in current society that would approach a similar stigma is paedophilia.²⁹⁶ The crucified person was by definition morally reprehensible: “..less-than-human scum.” (Rutledge, 2017, p.97). The disciples must also have understood the specifically religious shame that the cross represented. For Jews the cross was utterly offensive; according to Deut. 21:23 the hanged man is singled out as one cursed by God (Hengel, 1977, pp. 84-85, 87; Brown, 2008, pp. 532, 535, 855; Harrington, 2010, p.25). As Jesus warned, the disciples were scandalised, and surely must have felt ashamed of their teacher, as they began to think of Him in similarly shocking terms; as they realised that their hoped for saviour was about to undergo the public humiliation and total shame of crucifixion.

Jesus understood how totally disoriented they would be by the turn of events, and how frightened and scandalised they would become (Harrington, 2013, p.16).²⁹⁷ As He prayed for

²⁹⁶ It is interesting that HIV and paedophilia are both linked by sex. I am not intending to make any equivalence between HIV infection and the sexual abuse of children. However, it does indicate something about our present day society that of all human activity that might attract stigma, the gravest and most shaming stigma is reserved for activities linked to sex. I think it beyond dispute that within society as a whole, the stigma attached to commercial fraud, or societal attitudes of hostility towards refugees fleeing war, for example, would if we constructed a table, rank far below behaviours associated with sex and sexuality. As Weil puts it the state of affliction in social dimension attracts the “scorn, the disgust...and defilement that crime logically should produce but actually does not.” (Weil, 2009 p.70). I choose paedophilia to make the point about the shameful of crucifixion not just because paedophilia is properly regarded as especially abhorrent today, but also because of the ritual sexualised humiliation of crucifixion, insofar as the condemned were first paraded naked through the streets and then hung naked on the cross. Insults and taunting in regard to the naked body and genitalia would surely have been a part of the public spectacle. (Hengel, 1977, p.87; Rutledge, 2017, pp.78 footnote 15; 96 footnote 55). Brown (2010, pp.952-953) details the shame of nakedness itself in Jewish culture. That Jesus is recorded in the gospels as having retained some clothes on His way to crucifixion, indicates that He may have been spared this particular humiliation out of respect for Jewish custom by the Roman authorities. The evidence as to whether Jesus was naked or retained a loin cloth when crucified is inconclusive. For this thesis it matters only that as shameful, crucifixion represented and included an aspect of humiliation related to sexuality, and the disciples would have known this.

²⁹⁷ Borg & Crossan (2008, pp.111) argue that in the Gospel of Mark Jesus knows what will happen during His final week in Jerusalem. They state: “We need not attribute this to supernatural foreknowledge. Jesus must

the strength to accept the suffering that was His to bear, and trust God in this most dire circumstance, He also urges the disciples to stay awake and pray lest they enter into 'trial'.²⁹⁸ Jesus recognised that this time would be particularly dangerous for them. Physically they would face mortal danger; socially they were confronted with humiliation and disgrace, and in spiritual terms their faith and trust in God would be tested. As with the experience of HIV diagnosis they would be especially vulnerable to the temptation to lose faith, because they would be facing what feels like a full-scale spiritual assault.

As with the disciples it is only long after the gethsemane experience of diagnosis that the Christian can make sense of feeling so radically let down by God, as Martin felt. How could God let this happen? But what exactly has God allowed to happen? Physical illness and mortality must be faced by us all at some time. This is not what scandalises. The sense of being let down comes via the abandonment to public shame that diagnosis threatens.²⁹⁹ God seems to have led Martin into this garden of shame. It is the sense of being identified so closely with shame – the social stigma of the cross itself that is so scandalous and overwhelming for the disciples.

The plus sign of 'HIV+' on medical notes next to the name of each of my interviewees is written as a cross. For each of them, this cross impacts with overwhelming force in their gethsemane of diagnosis, and it too signifies shame. Like the disciples, the reality is both unwelcome and unexpected. They will be forever more associated with this cross, and at this point they too are scandalised under the curse of it.

7.6 The scandalising indwelling of HIV in the Body of Christ

The disciples could not have been scandalised by Jesus were it not for the fact that He loved them and they had been His companions. Within any friendship there are mutual expectations, but any expectations the disciples had were thrown into confusion. However,

have known that the noose was tightening, that the cross was approaching. He could not have been oblivious to the hostility of the authorities, and he may well have regarded his arrest and execution as inevitable - not because of divine necessity, but because of what he could see happening around him." In addition to the warning that Jesus gave the disciples, I think it reasonable to assert that Jesus knew His disciples well enough to anticipate, in quite some detail, how they would react to events.

²⁹⁸ Mk. 14:38; Mt. 26:41; Lk. 22:46.

²⁹⁹ As Susan Sontag (1989, p.37) notes: "It is not suffering as such that is most deeply feared but suffering that degrades."

Jesus anticipated that the disciples would feel ashamed of Him³⁰⁰ and that He would become the cause of shocking offence. We can only feel ashamed of someone with whom there is personal attachment, when we belong to each other in a close way. Beyond the broader social scandal of the cross, which threatens ridicule and public humiliation, there is the threat of separation from those whom we love and to whom we belong. The scandal of the Cross threatens the community of Jesus with disintegration, because the one around whom that community is centred embodies scandal. Brown (2008, p.153) notes that in Mark the greek word *adēmonein* used to describe Jesus feeling ‘troubled’ has a root connotation of being separated from others which causes anguish.

As Jesus suffered anguish at the thought of separation from His friends, and as He was first let down by those closest to Him, so too amongst the first causes of distress for the Christian diagnosed with HIV is the fear of separation and exclusion, through misunderstanding, fear or silence; their own and that of others. They fear that they will feel isolated from those whom they love and to whom they belong within their friendship groups, family or church. As already noted, the stigma of crucifixion had a specifically religious dimension. So too HIV stigma has religious implications. As I will show below, my interviewees experienced the fear that the baptismal cross, once signed on their foreheads as a mark of inclusion in the Body of Christ, has been superseded, replaced in their body by the cross of HIV, a mark of sin and shame which threatens exclusion.

After fleeing Gethsemane the disciples must have felt saddened, disappointed, frightened and confused. With the exception of Peter and his infamous denial, we hear nothing more of the apostles in the synoptic accounts until after the resurrection (Borg & Crossan, 2008, p.126).³⁰¹ The person diagnosed with HIV faces a similar experience of forced

³⁰⁰ This is evident in His prediction of their collective failure, and not least, in the prediction of Peter’s threefold denial of Him. Also see footnote 296.

³⁰¹ Matthew 27:3-10 does recount the fate of Judas who feeling ashamed of what he had done committed suicide by hanging; and in Acts 1:18-19 Luke offers an altogether more explosive version of the death of Judas. I am not including Judas in my descriptions of the disciples’ experience, as he had already abandoned Jesus before these events at Gethsemane took place. I also specifically emphasise the absence of the 12 male apostles here. It should be noted that the presence of Jesus’ female disciples is considered significant enough to be mentioned several times in all three synoptic Gospels between these Gethsemane events and the Resurrection: women are close by as Jesus makes his way to Golgotha (Lk. 23:27); women disciples witness the Crucifixion (Mk.15:40,41; Mt.27:55,56; Lk.23:49) and women watch at the tomb where the body of Jesus is laid (Mk.15:47; Mt.27:61; Lk.23:55).

abandonment. The cross of HIV will for a time isolate the person from others. They will bear the cross of HIV, just as Jesus did, alone, as He stumbled towards death.

7.7 Embodied scandal

I have argued that at Gethsemane the disciples were scandalised. I have emphasised the scandal of the Cross because as Rutledge insists “..the *shame* of crucifixion is more important for the determination of its meaning than the physical suffering.” (Rutledge, 2017, p.84).³⁰² I have drawn parallels with my interviewees’ experience of HIV diagnosis and described how the association with scandal provokes feelings of shame and fear. In Goffman’s (1986) classic terms it is the awareness one has of being discredited, having a ‘spoiled identity’ in the view of others. I have argued that the disciples had similar feelings at Gethsemane. And, I have described the fear of isolation from God and others. These are important dimensions of the gethsemane experience. However, these can be understood as ‘externally’ provoked insofar as these feelings arise from a perception of the attitudes of others (including God), and what others have done or will do. It is possible to think of all that I have described thus far, whether in regard to the disciples or my interviewees, as natural feelings of fear and great anxiety in the face of danger.³⁰³ Before leaving the experience of gethsemane and going on to consider crucifixion experience, I want to emphasise that the scandal of HIV digs deeper than just this awareness or perception of spoiled identity in the view of others. I am arguing that ‘embodied scandal’ refers to more than social stigma and something other than spiritual distress, although it includes both. I want to go beyond comparison with the disciples’ experience when the scandal of the Cross began to hit them, and more explicitly towards identification with Christ Himself.

As the object of public shame, during His trial, and ultimately on the Cross in public view, Jesus represented scandal. St. Paul makes the point when he speaks of Jesus becoming a ‘curse’ for us, and he perpetuates what is so religiously offensive when he uses this language.³⁰⁴ So I can say that Jesus became scandal. What is clear from my interviews is that

³⁰² The emphasis on *shame* is from Rutledge.

³⁰³ The danger includes the physical threat to life that the disciples faced and is faced by those diagnosed in terms of sickness and a confrontation with mortality; the danger of social exclusion, vilification and ridicule; and the spiritual dangers that attend the sense of God’s absence.

³⁰⁴ Gal.3:13. St. Paul also references Deut.21:23 which I have highlighted already in terms of the scandal of crucifixion in Jewish culture. In this passage from Galatians Paul treats questions of law and Christian faith. It is

by far the most painful and terrifying aspect of being scandalised is the realisation that the person now carrying the cross of HIV in their own body has become, like Jesus, the one who embodies scandal.

It is difficult to adequately convey this aspect of affliction because it is rarely brought to speech. However, it is essential I try, because it is intrinsic to the gethsemane experience and therefore important for understanding *who* it is the reader encounters in these pages. It is what Söelle calls “..mute suffering..” which renders a person silent. (1984, p.69).³⁰⁵ Cate recalls her diagnosis as a moment when she was rendered silent:

“It was strange, cause I didn’t cry, I didn’t really feel anything, I was, just, stunned really.”
(Cate)

Söelle argues that because it is impossible for a person in such an extreme state to communicate or share their experience with others, it cannot be the starting point for developing a theology of suffering because “...theology presupposes at least a certain amount of common experience...There is really nothing one can say about this night of pain, whether we find it in insanity or in an incurable disease.” Mute suffering she argues, presents the theologian with a border as un-crossable as the border of death itself. “Respect for those who suffer in extremis imposes silence.” (1984, p. 69). I understand Söelle to be commenting upon the inadequacy of theological formulae in the presence of such extreme suffering, and consider her argument persuasive. She does propose that a theology of suffering can begin from paying close attention to the humanity of those who suffer in this way, and by listening to their later accounts as they attempt to find meaning and communicate something of it. This thesis is one such account and interpretive attempt to find meaning. And as I have experience in common with my interviewees I want, at least to

not necessary to be concerned with a fuller exegesis here. For my argument it is sufficient to note that Paul uses similar language of embodiment. The religious category of ‘curse’ is just one reason why Paul writes in 1 Cor.1:23 that preaching Christ crucified is such a stumbling block for Jews.

³⁰⁵ Dorothy Söelle (1929–2003) was a German theologian and political activist. Her 1984 *Suffering* is a classic contemporary theological text. I refer to Söelle’s category of ‘mute suffering’ because I think it goes some way towards describing the extent of the trauma which renders a person silent and unable to speak. It is instructive for my argument, and serves to emphasise the importance of my point here about how this scandal is internalised involuntarily and immediately at the point of diagnosis. Söelle appreciates the challenge of both speaking and writing about such an experience, and I will go on to explain how this sense of embodied scandal develops in what follows, but it is important here (even at the risk of repetition later), because the depth of the trauma and the accompanying emotions begin and are experienced in some way, from the moment of diagnosis, even though words are yet to be found, if ever, that can articulate this aspect of affliction.

try to speak theologically about what I witnessed: the suffering that comes with awareness of embodied scandal, that they shared with me in the research interviews, but which I acknowledge, is often mute and difficult to put into words. Gloria was correct, to communicate the meaning of past trauma as it was once felt is challenging because we can only view it “..*with the eyes of after.*”

During the interviews, this deeper sense of embodied scandal was conveyed less in words and more through silences. It was communicated through so many deep intakes of breath before speaking, and every long sigh out; through each pregnant pause, and the stutters that gave hesitant speech a painful quality. It was communicated when shoulders slumped or tears surfaced as we sat quietly together.

Francis’ words come close to naming embodied scandal: “*The humiliation of it...It felt so incriminating, so dirty, so disempowering... dirt, disease, you know, decay, infection, disability, all those really negative words all spinning around in my head at the time.*” (Francis)

When Rosie gathered her thoughts, she allowed deep feeling, more usually contained and controlled, once mute, to attempt speech. She began with a breathy, tremulous, “*Oh boy....*”, and in those two small words I heard the effort and courage that is required to revisit trauma and allow the fragility of experience to be seen and heard. When Cate spoke of a “..*really deep soul cry.*” the deepest pain of all was re-membered between us. I recognised it. We each felt it and knew it though no words adequately named it.

After diagnosis they began to understand that they are afflicted not just by what is outside of them, but by something living in them. In His Passion Jesus embodied the scandal of crucifixion as His flesh became one with the Cross. So too, each person interviewed, knew that they were not just witnesses to something scandalous, but they had actually become physically, like Jesus, the scandal itself. Each person was aware of the religious aspect of the scandal of HIV. Echoing the two and a half thousand year old ‘theological myth’ from Deuteronomy, Rosie named HIV specifically as a sign of God’s curse, and she felt that in her body. Each person embodied scandal as Jesus embodied the curse of the Cross.

To say that these Christians embody the scandal of HIV is more than metaphor. As the HIV lives in flesh and blood I mean it in a physical ontological sense. It is carried in their bodies.

Theologically I argue that it puts them in the place where Jesus was, and that in them Christ can be recognised undergoing His Passion still. Through them the scandal continues in the body of Christ, and that has the power to scandalise others. They know it, and it cannot be forgotten. They felt the power of it first, in the gethsemane of diagnosis.

My God why?

7.8 Towards crucifixion – internalising the stigma of the cross

The way of the passion with HIV is neither neat nor linear. As the person struggles first to confront and then pick up their own cross, gethsemane experiences of fear, disappointment, loss and disorientation, are interwoven with crucifixion experiences of abandonment shame and alienation. The intensity of these passion experiences will vary. In fact, as an experience of abandonment, shame and painful isolation, the moment of diagnosis itself, may be more fittingly described as a crucifixion experience. The sense of embodied scandal, so shameful and disgusting that even God seems to have fled the site of affliction, becomes overwhelming. The cry of Jesus at the hour of His death ‘My God, why have you forsaken me’³⁰⁶ is felt and repeated. It is a question that must be confronted.

A focus on personal sin and the ‘guilt and innocence’ narrative turned inwards becomes the stance, the default position, from which to investigate the question. Typically, the most immediate ‘answer’ situates blame with the person. This culturally shaped narrative reinforced with theological messaging results in judgment:

“I was thinking, I was asking myself, was it because I wasn’t a good Christian, that’s why this kind of problem has befallen me? Because probably if I was a good Christian, maybe I would not have done certain things that led me to this.” (Piramo)

“My diagnosis made me feel that I had sinned, and God, from what people were saying, was punishing me for my indiscretions.” (Lazarus)³⁰⁷

³⁰⁶ Mk. 15:34; Mt. 27:46

³⁰⁷ Positive Faith. *HIV and Faith Matters. Why me?* Available at Positive Faith website & <https://www.youtube.com/watch?v=JHrsWhEH2p4&list=PLwWBS0fwuez8d-7sWaaQOyWgSf1cgSuHZ&index=1> [Accessed April 2019].

Gloria's observation of the human need for 'cause and effect' comes to the fore. Lazarus describes how the tendency to blame, prevalent in both European and African culture lead to the consideration of divine judgement.

"Not just in Western culture, in traditional Africa, if someone falls ill, somebody has to be responsible. Who would take the blame if someone died? Poor people blamed it on spells cast against them. Others were blamed because of their habits, like sex workers, the judgement was 'it is not surprising that they were infected'. If somebody died, there had to be someone to take the focus of the people's emotions. I think it is a universal part of human nature, to want to blame." (Lazarus)

Rosie considered whether her misfortune was part of God's punishment of her for leaving religious life.

"In my village, like, if you leave a convent, you don't have a steady life. According to a certain belief, you are cursed...Cursed, by God. After you left the religious life maybe God was annoyed with you, so you will not live a happy life." (Rosie)

Did her diagnosis confirm that God was scandalised by her?

"I told my parish priest that I was diagnosed with HIV, and straight away he told me, 'that is a punishment from God'...So it sort of put me down...How can God punish me?"³⁰⁸ (Rosie)

We have discovered that the horror comes with the dawning overwhelming feeling, that the person is being punished first, and then abandoned by a God who disapproves of what the person has done. Feeling 'let down' by God, (which may be common to other experiences of loss), has the added weight of divine retribution because HIV infection appears to be a punishment that 'fits the crime' of having broken sexual purity law, so perfectly. Reinforced by natural feelings of revulsion about this newly infected body, and because HIV has changed the sense of self, the person becomes aware of being in a body broken and 'sullied by sin'; to use Francis' word *"..dirty.."*. The weight of the Christian tradition associating sex, disease and sin creates a perfect storm of confusion and fear and a profound spiritual

³⁰⁸ Positive Faith. *HIV and Faith Matters. Why me?* See footnote 249 and bibliography under Films.

distress follows. The great lie is entertained:³⁰⁹ that God has punished and now abandons, not just because of what the person has done, but because of who they now *are*. It is a possibility that arises because of the interplay between internalised stigma and lessons learned previously in society and in church:

“Nothing teaches us more than experience. Experience is the best teacher. What you have seen before, you go by. I had already had experience of other people in the same situation. People who were known to have been HIV infected, they were shunned by members of their own family, and the community, so that was the yardstick by which to go...if I had disclosed to them, even to some of my closest friends, this would inevitably lead to the judgement, by most if not all.” (Piramo)

After the initial diagnosis each of my interviewees began to reflect upon their new status. The scandal of HIV became clearer as they began to consider the implications. Social stigma and the fear of judgement or exclusion, seems to confirm the greater cause of spiritual distress, that God is scandalised by the person. Such is the power of HIV diagnosis to cause a person to be scandalised, to lose faith, to feel deeply ashamed of who they are and what they have become.

Feeling ashamed is not the same as feeling guilty. Guilt may be appropriate when I have behaved in an unjust or unloving way, in regard to myself or others, or when I have failed to act in response to others’ suffering. Shame is beyond guilt. Karen A. McClintock describes it as feeling “condemned to the core” (2001, p.29). The person senses that their worth or integrity has been destroyed. HIV diagnosis places the person, at the place of Golgotha, the site of shame.

The cry of Ezra, ‘My God, I am too ashamed and disgraced to lift up my face to you’ is internalized.³¹⁰ Jesus’ painful question on the cross of shame, ‘my God why?’ seems to have found an answer.

³⁰⁹ St. Paul is clear that nothing can separate us from the Love of God in Romans 8:39. I have written elsewhere how Julian of Norwich considered this tendency to believe that God can abandon us because of sin as a type of ignorance based upon a lie which greatly hinders a person who loves God. (Manning, 2011).

³¹⁰ Ezra 9:6. The shame that Ezra felt was caused because many within the Jewish community had broken purity rules regarding sexual activity, which, interpreted as God’s law, risked divine punishment when broken. Namely that by taking foreign wives (or allowing their daughters to take foreign husbands), many men had desecrated their families and themselves, and by extension the wider community. It is considered a very great

This aspect of affliction can only occur because the people have faith in God. The question of being abandoned by God, or conversely of letting God down in some terrible way, arises because their relationship with God mattered. Each of them had already demonstrated a sincere commitment to follow Christ and live according to God's will for them in their lives. Their faith in God would not be let go of lightly:

"..as abandoned as I felt...as suicidal as I felt...There was always some hope, that things would...get better...as long as I just persevered, and if I let go of the idea of God then that hope would just disappear, and me with it." (Martin)

For each of my interviewees the question of having been abandoned by a scandalised God afflicted them, and tested their faith.

7.9 Embodiment and sexual sin

I want to avoid arguing for any presumption of or conflation between HIV infection and individual sin. Whilst I have shown that this connection is made almost automatically, I am in no way validating it. On the contrary I am saying it is wholly inappropriate. However, these interviews, with other research (UNAIDS, 2005; Mahajan, et al. 2008; Rueda, et al. 2016)³¹¹ does show that HIV gives rise to a kind of persistent 'communal sin'. Insofar as the insistence on infection as divine punishment is a religiously expressed manifestation of HIV stigma; and as long as this tendency to blame continues in society and church, it can be regarded as structural, in the same way that racism, or sexism may be regarded as structural sin.³¹² Gloria makes a similar point that directs attention away from the focus on individual sin and points towards a collective failure within the Church:

evil and a betrayal of God (Ez. 10:2; Neh. 13:27). It is considered so great a breach that to remedy the situation the foreign wives and their children are all sent away (Ez. 10:44). No mention is made of how the women and children would survive without the support of their now former husbands and fathers. Observance of the law and the restoration of purity to God's chosen people is paramount lest God's fierce anger over this be visited upon them (Ez. 10:14). Again, the tradition of linking sex and sin is in evidence. It is a relevant text because this sense of having broken a social and religious code is of similar potency to that which I argue attends the stigma of HIV which my interviewees each had to confront.

³¹¹ See also: The People Living with HIV Stigma Survey UK. *Changes and Challenges; Actions and Answers: National findings*. London, 2015

³¹² Jones (2006, p.195) makes a similar point regarding the tendency to attribute blame for sickness to the individual who is suffering, without taking account of the "structures of sin" that are not "easily eradicated from society."

“...part of the reason why I didn’t want to take the medication was that I felt, lack of support, and it was too much, to do by myself...Because sin is not just personal sin there is something like communal sin, and it is the failure to love in a sense.” (Gloria)

In this sense only, is it possible to make the presumption that where there is HIV there is sin, because we can witness the suffering it causes.³¹³ It is a significant dimension of the constructed cross of HIV.

Nevertheless, for those diagnosed this question of personal sin does arise. ‘What have I done to deserve this punishment’ is asked, even by those considered ‘innocent’. The question must be confronted because it is so inappropriate and spiritually damaging. Recall Paul’s story. He was infected as the result of a medical procedure in childhood but was not told about his status until he was 16 years old. There can be absolutely no question of personal guilt, but he remembers vividly how the ‘guilt and innocence’ narrative asserted itself and became an additional cause of suffering and a burden for him. Everything that Paul had absorbed in childhood, especially Church teaching relating to sexuality in general and gay sexuality in particular impacted upon him and justified the anger that increasingly possessed him:

“I was brought up, taught, that homosexuality was wrong. And I’m ashamed to look back and say this now, that I thought, you know, they were in some way responsible for my HIV. I suppose I was incredibly bigoted in that respect. I blamed gay men. And it took me, I don’t have that view now, but it took me a lot of years to get past that because I was angry, incredibly angry.” (Paul)

His was shame by association which he nevertheless internalised:

“I felt that gay people were not like me, they’re not normal...In terms of Catholicism...I was on the right side of the line, and gay men were on the wrong side of the line. And now because of them...I had got dropped over the wrong side of the line...[because] I had HIV now and HIV was so caught up with homosexuality at the time, and to some extent it still is...with those ideas of promiscuity and lax morals and homosexuality, and, so, It’s like, me,

³¹³Julian of Norwich, Long text n.27 (1998).

how could I, a Catholic from a normal family, get dropped over on that side of the line and get associated with people who would get up to these sort of things.” (Paul)

Paul became acutely aware of how HIV infection placed him, in his own view and that of others, ‘on the wrong side of the line’. He was sullied by HIV. He became conscious of the presumptive judgement attached to HIV within the church, and within himself. He knew that within this framework he would be judged an “*innocent victim*” nevertheless it turned him into an angry young man.

“It was easy to blame homosexuals and it was easy to be angry with them, because of the teaching of the Church.” (Paul)

Paul no longer entertains these feelings, thoughts and beliefs about others or himself, but it took him years to process his anger. As an adult Paul made sense of his experience of golgotha shame in more positive ways:

“..my perception of me as an individual, my relationship with the world, my faith. Everything altered.” (Paul)

Reflecting on this period in his life, he resents that he was captive to an anger that was not only unjust but absorbed him and distracted him from his own grieving and healing. There is no-one immune from the stigma of the cross of HIV.

7.10 The cross of shameful self-loathing

As gay men are over-represented in the HIV population, I think it is important to notice how for the gay men in this study, the possibility of being unworthy of God’s love painfully surfaces in a particular way. Again, the roots are to be found in religiously received notions of divine retribution for transgressing the rules of sexual behaviour, but in their case it is not only their (possibly sinful) behaviour that must be considered but the very nature of their desire to love and be loved.

Above I reported how the theologians I interviewed were compelled to question that teaching, across all Christian traditions, which claims that gay sexuality is a type of disorder, because of their encounters with gay men living with HIV or dying with Aids. Recall how for James Alison it was not only a theological issue to be debated, but a personal challenge with which he had to wrestle. He concluded that he could no longer uphold the teaching of the

Roman Catholic Church. Sebastian Moore, OSB, 'confessed' that he too reacted to HIV as it emerged within the gay community, but his first response was closer to that of Paul's which we heard above: *"I was ecclesiastically a bit homophobic...so, in that context, I must confess, a spontaneous reaction to the outbreak of AIDS, was well, serve them right, not quite that, but, yes, it was a kind of punishment for something wrong..."* It is an attitude which Sebastian came to regard with *"horror"*. In the later years of his life, after many years of personal struggle Sebastian also rejected Catholic Church teaching in regard to same sex relationships, and joyfully 'came out' as a gay man.³¹⁴ Both examples serve as reminders of how in the case of a gay man (or woman) affected by HIV the guilt and innocence narrative asserts itself, and is powerfully reinforced with teaching that regards same sex desire as contrary to natural law, and disordered (CCC paras. 2357-2358); teaching that asserts gay sexuality constitutes *"a more or less strong tendency ordered toward an intrinsic moral evil"* (CDF, 1986, para. 3).

So too, the gay men interviewed had to revisit painful questions of self-worth as the shock of HIV diagnosis raised the suspicion that what was learned in childhood is true: that they are ontologically disordered and any expression of their sexuality is intrinsically evil. After many years of struggle growing up, Tiago thought that he had resolved these questions of his acceptability before God as a gay man. Intellectually at least, he had concluded that expressing love for another man could not be morally evil because:

"Where there is love, [there] is the presence of God and sin means the absence of God."
(Tiago)

After diagnosis God's absence seemed to be conclusive judgment, and Tiago felt that he was *"..being punished for being gay.."*

Francis spoke about how, as a teenager, he would slip away from home on secretive trips to attend charismatic healing services. At the time he was not quite sure what it was he needed healing from, but he knew he was different, in a negative way. He suspected that

³¹⁴ Sebastian was an academic theologian and author, and a monk of Downside Abbey. As part of my preliminary research I was the last person to record an interview with him. He often spent Sunday evenings in my company and with members of Positive Catholics during retreat weekends held at Bainesbury House in the grounds of Downside School. He died in 2014 aged 96.

there was something not quite right about himself. What he called a “...nagging doubt...” about his self-worth:

“I was always aware, it always felt like there was a sort of, a stone in the shoe, of my spiritual journey. And it was around my sexuality in the broad, but my sexual orientation specifically.” (Francis)

I am not arguing that the affliction of embodied scandal was lesser or greater for the gay men, than for others. I am arguing that when their faith in God was tested, Tiago, Martin Joseph and Francis had to consider the dreadful possibility that the answer to their question ‘why God?’ was not ‘because of something you have done’, but ‘because of who you are’; and that is not something that they could change.

HIV diagnosis will often reopen old wounds. Past barriers to inclusion that increased the sense of isolation from church and family are also re-presented:

“I certainly couldn’t go back to my family as a gay man living with HIV.” (Martin)

“With my parents it would be ‘I know you kind of know that I am gay but actually here’s the evidence. All of that...propaganda that we were saturated with in the eighties about gay people being [a] conduit really, for this disease, those worse fears have come true. So it would be a reinforcement for them, that ‘Oh my God our eldest son is Gay, and Oh my God now look, the fruit of that is this disease’. That is just a humiliating place to be.” (Francis)³¹⁵

Not only for the gay men, but for each person in this study the temptation to lose faith and trust in God in this dire circumstance is apparent. Similarly, every person expressed their anxiety that talking to others in family, or parish, risked rejection, misunderstanding and judgement. The sense of embodied scandal may be dismissed relatively quickly by some;³¹⁶ for others this internalised self-loathing persists for years, as a kind of depression. Each

³¹⁵ For a discussion of the essentially sinful anthropological understanding attributed to gay sexuality in official Catholic Church teaching see Crowley, 2004; Crowley, 2008.

³¹⁶ I do not intend to suggest that the suffering of embodied scandal is ever addressed in a short time. I mean relative in relation to the experience of others living with HIV. As I have argued affliction is never forgotten. The awareness of embodied scandal remains with any person living with HIV although the degree to which this is internalised or permitted to create suffering will vary from person to person. In my experience it is something that can only be addressed or processed over months and years rather than days or weeks.

person has had to entertain, however briefly, the great lie: that God has fled because they are unlovable; and in large part, this doubt has causal roots in religious formation and belief.

7.11 Summary

In this chapter I have described how each of my participants was thoroughly shocked by the event of their HIV diagnosis, and how it cast them into a state of confusion, fear and anxiety. Their experience like that of the disciples was attended by denial of and resistance to a reality that they were not prepared for. In their gethsemane of diagnosis they suffered affliction, which only deepened as they became increasingly aware of the scandal of the cross. Moreover, as each of my subjects came to understand themselves as the embodiment of scandal, I have argued that they can be identified with Christ Jesus who before us embodied the scandal and curse of His Cross at Golgotha.

Chapter 8. Between cross and resurrection

8.1 Introduction

I have provided evidence that an HIV diagnosis creates a profound crisis of trust in a loving God. Fear and isolation is felt most intensely on the constructed cross of HIV where it appears that as others are scandalised, even God is scandalised, and our participants felt abandoned by Christ their saviour. My argument proceeds by showing how and in what ways my participants found the strength to confront their cross of HIV. In this chapter and continuing in the next, I will show that the “inexhaustible loving which endured through Calvary does not abandon those for whom Calvary was undertaken in the first place.” (McDonagh, 2007, p. 45).³¹⁷

After Jesus was shamed to death, He was laid in the tomb. The women seem to have understood more than the male disciples.³¹⁸ They anticipate His death, and in mourning come to anoint His body as was the custom. But there is no body and they find the tomb empty. Once again expectations confounded. The women encounter mysterious angelic figures, who reassure them that Jesus has risen and will come to them shortly. The angels tell them not to be afraid. The women remain confused and feel both fear and joy.³¹⁹ In Luke the angels ask them ‘why do you look for the living amongst the dead?’³²⁰ The women will not find Jesus in the tomb. They must find Him, or more to the point, Christ will find them elsewhere.³²¹ So too those diagnosed will not discover new life until they have looked into the darkness of the tomb and mourned for what has been lost. The risen Christ will be found elsewhere. Those ‘places’ where one expected to find Christ before must be left behind. In the meantime, the angels appear to the women – ‘stay with it’ they seem to say.

³¹⁷ Calvary is the Latin translation of the Aramaic Golgotha

³¹⁸ I am noticing a point of contrast with the male apostles who, as I have explained in the previous chapter, did not anticipate the events of the Passion. Their incomprehension and the very different expectations they had of Jesus the Saviour, in addition to the natural terror of the events at Gethsemane, were the basis for the profound shock they felt. I am not claiming that the women anticipated the Resurrection. However, that women often understand when the men fail to is apparent in the synoptic gospels. See for example the story of the woman who anoints Jesus at Bethany in the house of Simon the leper in Mk. 14:3-9 and Mt. 26:6-13. Also, in Mark and Luke the women who tell the other disciples that Jesus is risen are not believed by the men who consider them foolish Mk. 16:9-11; Lk. 24:9-26. (Harrington, 2010, pp.33-35).

³¹⁹ Matt. 28:5; Mk. 16:5; Lk. 24:4; Jn. 20:12.

³²⁰ Lk.24:5

³²¹ Matt. 28:7-10; Mk. 16:7.

‘Don’t lose faith’. They encourage them and despite their confusion, the women find strength in that.

8.2 Letting go – Accepting – Strengthening

To begin to carry the cross of HIV means dealing with the natural fear of considering and confronting it insofar as it represents death. As I hope is becoming clear, there are times when this fear alone makes one want to run from it; at other times my subjects have felt crushed under the weight of it. To carry the cross of HIV is to carry the symbol of death bodily as Jesus did. Jesus knew that His cross would be the means of His execution and shameful death. He too had to confront the instrument of His own torture knowing that it would end in crucifixion. For the Christian the cross of HIV is a constant reminder of mortality, but it need not lead inevitably to a shameful death. It need not end in crucifixion on the cross of HIV, even though the person will forever be associated with it. How can the Cross, the symbol of shameful death become a source of hope and new life? The challenge is how to live beyond gethsemane fears and confusion, so that the cross of HIV does not lead inevitably to a shameful life. How to move through the confrontation with death, beyond the stigma, and rise again to new life, shaped by HIV and faith? How is love to be remembered when the pain of love lost seems so final?

In pastoral ministry I have met those who are unable to get beyond HIV as affliction. That is to say they remain nailed to the cross of physical, social and spiritual suffering. Of the people I interviewed, Gloria embodied a state of ongoing affliction more than anyone else. Her physical suffering never let up and towards the end of her life she was in constant severe pain. Due to her lack of adherence to ARV treatment over many years Aids defining cancers eventually killed her. She kept her HIV diagnosis secret from her family and from most of her friends. A person is most in need of support when feeling isolated and afraid; but it is also when they feel at their most vulnerable. Feeling let down by God, or life, or oneself, the further vulnerability of disclosure can feel too great a risk to take without adequate support. This was a risk Gloria rarely took, and so she remained isolated from and unknown to those she loved. It was Gloria who most prompted me to think about why the ‘how did you get it’ question is so disturbing and unhelpful. She spoke with me at length about the time that she was invited to share her own theological reflections on HIV with a group of priests. Gloria had post-graduate qualifications in theology. She had carefully

prepared a short talk with the theme 'Be not afraid', drawing from the thought of Pope John Paul II, which she hoped would be helpful to the priests in their pastoral ministry. Her heart sank as she realised that they seemed less interested in what she had to say and more concerned to know how she became infected with HIV. Afterwards she asked the priest who had organised the event how it went:

"(He) said to me 'It was very good, but we wanted to know how you got it. It would have been more interesting for us, to know how you got it, and more about your history...'"

(Gloria)

She felt offended and diminished; that the value of her theological reflection had been dismissed. She connected this dismissal not only to a *"..voyeuristic.."* preoccupation with transmission, but also with her broader experience as a woman in the Church. She felt that the priests had downgraded the value of her considered reflection in part due to prejudices rooted in a clerical male dismissiveness of women, and partly because they seemed preoccupied with how she was infected.

"They didn't take seriously my reflection on my own experiences. They didn't consider them as considered reflections which have a pedagogical value." (Gloria)

The time of affliction with HIV interacts with other areas of individual vulnerability, and exposes them. The HIV infected person is a particular person. Perhaps an HIV infected woman, or gay man, or drug user or asylum seeker or unemployed. Very often the scandal and stigma of HIV intertwines with existing spoiled identity like vinegar on a wound. The sense of embodied scandal is often wrapped around a pre-existing awareness of spoiled identity because of gender, ethnicity, sexual orientation or social status. Gloria never stopped resisting the second class citizenship that she felt was imposed upon her as a woman in a patriarchal Church. She felt the pain of that exclusion acutely, as long as she lived, and bore it with the added sense of marginalisation that comes when HIV remains painfully secret. Gloria lived for years at the golgotha site of physical pain, spiritual isolation and terminal humiliation.

None of my interviewees can forget their own gethsemane or golgotha experiences, but they have moved, more or less, beyond the state and time of affliction. Suffering remains, but it has been reinterpreted. For any Christian, certain facts of this new life with HIV must

be accepted and integrated in a positive way, if they are to flourish as God intends (Messer, 2013). Each person had to address areas of conflict within their own lives which became more urgent after diagnosis. For each of them this would mean something unique and personal, but there are some similarities. For all those interviewed, diagnosis exposed and tested their understanding of God. As Christians each of them wanted to trust in God, but in order to commit to the same prayer of Jesus, 'not my will but your will be done', and move in the direction of acceptance of the cup of HIV, they each had to reconsider matters of faith and doctrine. A process of acceptance, strengthening and letting go is necessary. Again, this process is not linear, but these components, like the interlocking cogs of a timepiece, are each important to enable personal growth that opens the way to healing from the wounds of affliction.

8.3 Letting go

The meaning-map of faith must be redrawn, because it has been defaced by shock, fear and stigma. I will go further, what is at stake here is the possibility of love itself. As has been shown already, in the lives of my interviewees, their own love-able-ness, and their capacity to give and receive love, has been called into question. So too the quality or constancy of God's love for them has been doubted. This sense of love's lack has been expressed variously as self-loathing; as experiences of God's absence; and within the church as judgement and blame. Within this context, for Christian faith to endure the choice to believe in love, despite not feeling loved, must be made. Söelle argues that in the midst of these dire circumstances "the capacity not to stop loving depends on faith in God" (1984, pp. 156-157). This echoes Martin's conviction that without faith "*..hope would just disappear, and me with it.*" It is a matter of spiritual and physical survival. To continue to believe in love when one feels so unloved and unlovable requires faith. But for faith to survive, each person has had to learn to believe differently and to live out of faith in a new way. This involves both acceptance and rejection; learning and unlearning.

I do not want to be distracted by debates around moral theology narrowly understood. I do not intend to debate theological approaches to condom use, or sexuality, or sex with-out

marriage, gender, contraception or divorce. So much is already written elsewhere.³²² I want to stay with the experience of the people in this study, and show that a shift in their understanding of their relationship with God and the church became vitally necessary.

8.4 A crisis of authority - growing into adult faith

It is relevant to note that each of the people interviewed has come to reject much of what they understand as official Church teaching on these matters, because they consider it variously intellectually and theologically flawed, pastorally unhelpful, or dangerous to health. For example, no one had anything but disdain for the official Church teaching, (popularly understood), on the use of condoms.³²³ The question of condom use is most often resolved quickly:

"..there's no way I am going to put a sexual partner, at risk without using a condom. So that (Church teaching) was very easy to discount." (Paul)

"According to me, to live in accordance with official church teaching it is not sensible. It would put people I love at risk. It is not practical or sensible according to me, no." (Rosie)

Gloria made a more sophisticated argument linking sexual intimacy with what it means to be fully alive:

"...human sexuality...enables us to experience and, offer, love, to one another...an intrinsic good of human being, if it is done with an awareness of what a human being is. So, it teaches us how to be human...condoms...allows people to love one another in an intimate vulnerable way [and]...to be alive is better than to be dead." (Gloria)

Other issues such as gay sexuality have been more difficult to address, but the teaching that gay sexuality is disordered is explicitly rejected by all but one of my interviewees.³²⁴ Their conscious rejection of much of what they received in childhood has been painfully realised.

³²² Some of the writers that discuss issues of moral theology and issues raised have been referred to in the introduction, and chapters two and four.

³²³ I would argue that the official teaching of the Church on this issue is not as clear-cut as it is perceived to be; and it has been consistently disputed by theologians, and defied in practice by Catholic health care professionals. Whether the official teaching has been understood adequately or not; and regardless of whether one agrees with it or not; it has been widely received in the public domain and understood by most people as an unequivocal and total prohibition on the use of condoms, even for sero-discordant married couples. I refer the reader back to my account of the 1989 Vatican conference in my introduction and 'public perception' in chapter two.

³²⁴ Lazarus did not make any reference to issues of gay sexuality

This letting go of what is unhelpful can be understood as one aspect of carrying the cross of HIV. My interviewees have not come to their conclusions flippantly. On the contrary, each of them has wrestled with these issues because of their attachment to and respect for both the traditions and the teaching authority of the Church. Nevertheless, each person had to abandon official Church teaching that could no longer be sustained under the weight of this particular cross.³²⁵

However, letting go of previously received moral norms can result in the feeling of not quite belonging 'properly' any more. No longer being a "*good Catholic*" as Paul put it; or being an "*a la carte catholic*" in Joseph's words. The letting go of doctrine that one no longer believes is painful, because it exposes division within the Body of Christ, and threatens conflict. It raises questions regarding a person's right to identify as a member of the community to which they belong. It also poses the question of whether or not they wish to belong any longer. Eventually, Tiago, Gloria and Cate found new churches where they felt more welcome and valued; less judged; more accepted and understood as they are.

This break with Church teaching is also a break with the authority of the Church and those who represent it. I believe that in the lives of our subjects, it is an essential move, but no less disruptive because it is necessary. It provokes anxiety at least, not dissimilar to that experienced when a young adult first defies their parents, or realises that not all adults can be trusted. In this sense it is a part of the process of growing up in faith: a necessary step away from a childish reliance on authority and towards adult discipleship. Or put another way, growing beyond obedience to the (formal and informal)³²⁶ rules of church membership which have been equated with faith and Christian identity; and towards that responsibility which comes with obedience to one's conscience, and a more mature understanding of

³²⁵ This rejection of Church teaching sometimes arose because the doctrine is considered untrue e.g. regarding gay sexuality. In other cases it is a question of reconciling the norms of Church teaching and membership with the reality of one's life experience and situation. For example, at the time of interview both Cate and Lazarus first marriages had ended. For different reasons they were not sustainable. They both had to make decisions that weighed the official Church teaching regarding marriage, and their obedience to that teaching, against the love that they felt for and shared with their subsequent partners. In her study of Catholic women living with HIV and their understanding of Church teaching in regard to marriage Reimer-Barry (2008) finds a similar dispensing with official teaching that cannot be sustained; as do Liboro and Walsh, (2016) in their study of Catholic gay men living with HIV in Canada.

³²⁶ By 'formal' I mean official Church teaching. 'Informal' refers to other beliefs held within the church that may or may not be magisterial teaching but are nevertheless inculcated as part of local ecclesial culture e.g. the belief expressed by Lazarus, Piramoi and Rosie, that misfortune in life is a sign of being cursed by God.

what it is to be an adult Christian. It can be scary. As with Martin, it means letting go of so much that previously made him feel safe.

As I showed above, in most cases, practically speaking, my interviewees' Catholic formation consisted of obedience to Church teaching as the highest value, clearly stated by Martin: *"Do what the Church tells you to do."* Or as Paul put it: *"The priest was in a position of authority and you did not question him, you really didn't...what he said went...It was that way or nothing!"*

Obedience to Church teaching was and is, for most Catholics, directly linked to the Sacrament of Reconciliation. With the Eucharist, the Sacrament of Reconciliation, (still referred to as confession), most signifies ongoing inclusion in the life of the Church. The validity of confession as a practice that can be restorative and healing is not the focus here.³²⁷ Rather, consideration of confession in the lives of those interviewed will reveal why, for adult faith to survive, it is so necessary that any childish reliance on the teaching authority of the Church (or the church), and those who represent it, be abandoned.

I am less concerned with the obvious pastoral failure of the clergy in the following examples. I want to build upon the evidence of an ecclesial culture of obedience in the formation of my subjects and show how deference to authority heightens the sense of faith being tested and adds to the affliction of HIV. For Tiago and Gloria, seeking the 'parental' approval of those who represent authority in the church increased their suffering. As with all those interviewed, for faith to survive diagnosis, their expectations of the clergy and the wider church will need serious adjustment.

As a young man in formation for priesthood Tiago had wrestled with his emerging gay sexuality and the implications, especially in terms of priesthood:

"I was celibate. I was trying to explore, to share sometimes confusing feelings. Not sexual acts with anyone, just the feelings...that was what I was trying to explore.." (Tiago)

³²⁷ With the Sacrament of Reconciliation, (also called confession or penance) the Sacrament of Healing (also called Sacrament of the sick or anointing), are Sacraments of healing in Roman Catholic tradition. James 5:14-16 recommends that if anyone is sick within the Christian community they should present themselves to church elders to be prayed over and anointed with oil. They will be raised up and any sins will be forgiven. James recommends the healing that is experienced when Christians have confessed their sins to one another and are prayed for, anointed and forgiven within the community of faith.

He turned to a priest for advice and guidance. It would be the start of a lengthy battle for Tiago as he sought acceptance within the Church. Instead of advice it was 'Father' who made sexual advances:

"[After] the confessional, we had Mass, and then dinner at his place, and he tried it on with me at that time. We had an argument and I left. We met again, the same happened."

Tiago sought understanding and guidance "...but he was trying to explore other things on me. It was very shocking..."

"So I went to another priest and say what was going on. Then everything came, basically to public knowledge within the church, and that was an impediment for me to continue to be a seminarian, because I was saying I was openly gay at the time." (Tiago)

Tiago felt that he could maintain the discipline of chastity and celibacy that ordination required. However, he could not accept that his sexuality was disordered. Neither could he accept that he must remain silent. After speaking openly about his feelings, and having reported the inappropriate advances of a senior priest, he was expelled from the seminary. When he returned to his home parish, his 'outcast' status was confirmed:

"...my parish priest asked me to not go to Mass because it was a shame for the community...I was asked not to attend my own church because people were uncomfortable with my presence. That is the church I was attending as a child as a teenager, that was my church!" (Tiago)

Tiago went to University. Whilst there and for several years afterwards, he continually sought affirmation from clergy, very often via confession. However, he never received the affirmation he looked for.

Gloria told me how much she enjoyed the sacrament of confession. She chuckled when she told me that our meeting on a Friday during Lent for the purposes of this very personal interview appealed to her "*catholic sensibilities*".

She had been contemplating whether to stop taking her medication in order to hasten her death. It was to 'Father' in confession that she turned to ask whether this would be the same as committing a mortal sin. She did not find a satisfactory answer. Looking back upon it, she realised that she had expected too much:

“The feeling of inadequacy must come to them, overwhelming, how do they deal with this? ...a human being, who is questioning whether their life is, em, worth living or not, and feels bad about asking that question in itself...” (Gloria)

“By virtue of being an anointed priest one is not in a position to give answers to deep existential questions and it is actually quite unfair to ask the priest to be in that position, or to expect them to be able to give such answers.” (Gloria)

At other times Gloria found the sacrament consoling. The anonymity of the confessional allowed her to say what she found hard to accept, and what she felt could not be said elsewhere. But she was no longer expecting answers:

“One time, I went to confession, and I don’t remember what it was, but I was crying, and the priest said, ‘Oh, I did not mean to make you cry’, and I thought, oh sweetie darling, it is not you who made me cry, it is my heart that is crying, and it is good, it is a sense of liberation.” (Gloria)

As we have seen already, Gloria’s sensitivity to her ‘second class status’ as a woman in the church was heightened after diagnosis. Similarly, in this example she expected too much from those in positions of leadership, and was disappointed. Eventually she adjusted her expectations and availed herself of what solace she could. All my interviewees reported similar experiences, not only with clergy, that confirmed their fear that acceptance from their wider community of belonging, the church, was simply not available. Those in authority could not be relied upon to understand the challenges of an HIV diagnosis much less provide satisfactory answers to difficult moral questions.

Tiago’s shaming had started long before his HIV diagnosis. The rejection that he would continue to experience had begun in his youth. HIV diagnosis amplifies any previous experiences of alienation and shame. In common with all those interviewed, diagnosis exposes any residual self-loathing, and brings it painfully to the surface.

Rejecting certain Church teaching is not just an intellectual exercise, weighing moral arguments and arriving at conclusions in good conscience. It is also an emotional letting go of ‘Father’. It is the necessary abandonment of the parent-child relationship that was formed in childhood, where ‘Father’ represents the Church, and the safety, certainty, reliability and approval of a parent. In consideration of the conflict between Church teaching

and lived experience, for my interviewees, in order that faith in and relationship with God survive, significant Church teaching on issues of human sexuality and relationships in particular had to go.

However, I am arguing that this is an important move because it goes beyond matters of church norms, doctrine or moral behaviour; beyond even the sense of belonging within the church. It is also about relationship with God. Insofar as obedience to authority was perceived as the measure of not just faith but also right relationship with God, the relationship(s) my interviewees had with other members of the church, especially those in authority, had implications for how they understood their relationship with God. For my interviewees religious culture appears to have privileged an image of God the Father as a parental authority figure who requires right behaviour; and the church is the community within which God's expectations of us are both learned and enforced. When HIV stigma, judgement, and lack of understanding combine to produce the sense of exclusion from the life of the church, the idea of divine retribution and a God who punishes is embodied within the Church – just when the embrace of the God who loves without condition or hesitation is most needed.

So, the meaning-map of faith has to be redrawn not only in terms of doctrine, but the Father-God of childish imagination, the god of reward and punishment must be let go. This god whose love is conditional upon behaviour, reinforced in the imagination through childhood formation and ecclesial culture, is the god who terrifies; the god so scandalised by HIV that he abandons his child. To paraphrase Julian of Norwich this is the false god sent by the devil to afflict us when we are most in need, so that we become so preoccupied with the absence of love and goodness which is called 'sin' that we forget the everlasting and constant love of 'our good Lord'. This is the false god of the great lie (Manning, 2011).³²⁸

For each of my interviewees there is a time of absence felt, a necessary emptiness when this relationship dies. A time of mourning, of gazing into the empty tomb, wondering and waiting. Not yet understanding where 'our good Lord' has gone or when He will be met again.

³²⁸ Julian of Norwich, Long text para.76 (1998).

Christ will be encountered not in the empty tomb of a false god but in unexpected ways and places. The childishly imagined god is exposed and must be abandoned. The person's capacity not to stop loving depends on faith in a different God. With a childlike simplicity Paul expresses the more mature faith in God that emerged for each of those interviewed, to replace childish belief:

"I find great comfort in faith...I really don't know whether there is a God or not, hand on heart. If there is a God, it is somebody who is kind, is forgiving...understanding...So if there is a God, that's how I imagine God to be. More like a nice grandfather rather than a scary judge like figure, or like a grandmother." (Paul)

This is the test, the trial that Jesus warned His disciples about. What emerged for Paul is faith based not upon the security of knowing, but one that allows for not-knowing, and crucially, as with all those interviewed, he had to reimagine God.

8.5 Love's absence in the face of death

It is well established that coming to terms with a serious illness is a process. Before acceptance there is denial and resistance to the new reality. So far, most of what I have written describes the struggle between the time of shock and acceptance. I prefer to speak of 'giving way' rather than acceptance, because acceptance may suggest passivity, whereas giving way requires that an active choice be made. It involves the necessity of letting go of previous attachments and is suggestive of how coming to acceptance is not just intellectually achieved but requires a response that is also bodily and spiritual. To give way one has to physically and psychologically loosen the tight grip. Giving way is not the same as giving up. In Christian terms giving up in the midst of suffering is the temptation explored already: to lose faith in God and deny the possibility of love. When the person feels that further resistance to 'what is' has become futile, or because they are exhausted and so weak; giving way is the only alternative to giving up. Giving up comes from a place of resigned defeat, whereas giving way allows for the residue of hope that Martin spoke about. It is a more positive move because it reflects a choice that is made and includes a willingness to trust. Giving way is the occasion for both an expression of faith and the test of faith. After the manner of Jesus, it is the choice to trust God in dire circumstances. It can also be understood as the moment when the person accepts that the cross to be carried cannot be avoided.

If never before, HIV diagnosis confronts the person with mortality and finitude:

"...your mortality has a date. And as a reasonably young man that is not something that you think about." (Francis)

For each person in this study, HIV diagnosis was experienced as 'a death sentence' regardless of whether they were diagnosed in the period before or after the introduction of ARVs. Joseph let out a long deep sigh and his speech slowed as he told me:

"I thought it was a death sentence. First thing I thought was, I am going to die now... Diagnosis made me conscious of my mortality...the issue of my mortality was very much in the foreground." (Joseph)

We are back again at Golgotha where the cross makes thoughts of death unavoidable. That HIV diagnosis is a confrontation with mortality may seem to state the obvious. However, it is not only because of the fatal reality of HIV infection that death is experienced as real. Whilst God's absence may be felt by any person facing a life threatening sickness, the impossibility of understanding, and loving acceptance from others, is not inherent to the experience.³²⁹ As I have argued, after an HIV diagnosis the rejection by others is always feared. HIV stigma signifies 'social death'. The possibility of inclusion and the mutual enjoyment of friendship, which depends on being known and accepted by others as you are within a community of belonging seems unavailable.

Similarly, as HIV relates to sex, beyond social isolation from family, friends, church or God, the intimacy enjoyed in sexual relations, also seems closed off:

"I felt extremely alone, lonely, and isolated, and I thought it would prevent me from having a partner ever, ever after, and so I felt extremely isolated." (Joseph)

Sexual intimacy is in jeopardy. The spoiled body is now too dangerous to be embraced. Joseph and Francis gave words to this sense of being literally untouchable.

Of all the senses touch requires mutuality. One cannot touch without being touched.³³⁰ The intimate touch conveys love, acceptance, and delight, and no more so than through tender-

³²⁹ For example a person diagnosed with Parkinson's disease does not automatically consider whether others are likely to judge them to be deserving of this illness. Sympathy and loving-kindness will usually be expected.

³³⁰ See interview with Timothy Radcliffe in chapter four.

erotic embrace.³³¹ It seems that this embodied loving that permits intimacy beyond words, is out of bounds. Sebastian Moore famously said that “desire is love trying to happen” (2008, p.143) and it is within the sexually intimate encounter that the deepest human desire strains towards loving union.

I do not intend to romanticise all sex, but it is true to say that within loving sexual intimacy the desire to enter into the mystery of God’s love finds expression through the flesh to flesh encounter with a beloved person. In this way the erotic loving embrace allows for the possibility of embodying love that transcends mortal limits. The intimacy, thrill and wonder of loving sexual union is a foretaste of Divine intimacy and the fullness of life. The loss of this possibility also signifies death:

“This is precisely what death is, separation from everything life can actually signify.” (Söelle, 1984, p.156). When God’s absence seems final and love’s possibility lost within the depths of affliction the person encounters death. A combination of fears of God’s love withdrawn, and human intimacy impossible, sears death into the soul and threatens to extinguish the capacity for love.

Here I am getting at the internal core of the experience where embodied scandal is magnified and concentrated. Feeling cut off from God’s love is the defining fear of the gethsemane experience. Feeling isolated and abandoned by the community of belonging is the way of the cross. Feeling untouchable and not worthy to be embraced signifies a crucifixion of desire, after which only the gloom and darkness of an empty tomb seems real. Each person in this study has had these passion experiences. They had to undergo the range of emotions that accompanied these events in their lives, and give way to them.

8.6 Giving way to oneself

Francis’ had to let go of his faith-meaning-map within which God’s will for him was understood as personal holiness through a kind of spiritual athleticism dependent on his own efforts. In his confrontation with finitude his former understanding of spiritual life now seems useless:

³³¹ Eroticism contributes to love when it remains connected to qualities of tenderness and concern for the other within sexual relationships; it is destructive when “..an egoistic cultivation of pleasure wins out over mutual exchange.” Ricœur, 1964, pp.137-138.

“So the measure of my spirituality would have been around my activity, how many rosaries could I say, how many religious services would I go to, how many devotions, how much theology could I study, how, how, ascetic or disciplined could my practices be. I was very very conscious of my responsibilities in what felt like almost a contractual relationship with God.”
(Francis)

“..being diagnosed...if we use the spiritual athlete metaphor it’s a bit like breaking your leg.”
(Francis)

The self-reliance expressed by his metaphor of spiritual athleticism was useless. The god whose love is conditional on what we do or fail to do, redundant. Francis, like each of my interviewees, had to give way to mortal vulnerability:

“Having to reflect, that I am living with mortality, in my body, and I don’t know how long I will have to live with that sense of mortality. So I have to kind of accept myself as I am, and I have to hope that God accepts me as I am here today”. (Francis)

Giving way is ceasing to resist ‘what is’. In this move towards acceptance of mortality, Francis understood his need for self-acceptance as imperative. Because, when death threatens, love without qualification or exception becomes more urgent. The choice becomes one of living life and meeting death shame-fully; or living out of love. For the spiritual journey to continue any ‘stone in the shoe’, any impediment to the spiritual journey must be jettisoned as surely as a person in a sinking boat throws dead weight overboard in order to stay afloat. For Francis and each of the gay men this meant that further resistance to their own sexuality had to give way to self-love. Each person in this study had to give way to the reality of their own mortality, and if love could not be found in the empty tomb they had to give way to ‘what is’. They had to learn to love themselves as gay, straight, women and men; physically fit or in weakened bodies; spiritually ‘strong’ or filled with doubts. Whatever their circumstance or condition they had to try at least, to love themselves as they are, and regardless of what anyone else might say or what they had been taught, choose to trust in a God of love who can do the same.

8.7 Giving way to necessary suffering – towards strengthening

Finally, I want to share Joseph’s experience of giving way because I think his story contains insights which are instructive for any Christian who faces affliction. His story most explicitly

coincides descriptively with the physical suffering that Jesus endured on the Cross and serves as a summary that may be applied to all the experiences above. It is a mystical experience that will take us in the direction of strengthening and healing and how suffering can be understood as liberating and redemptive.

Joseph confronted death on three occasions. The first was with his HIV diagnosis. Only a few months later, he was diagnosed with advanced lymphoma cancer, an Aids defining disease and was told that because the cancer was so aggressive, he had only a matter of weeks to live.

"It was very unclear whether or not I would survive, or not. It was all very upsetting, and, dangerous really." (Joseph)

Contrary to expectations, the cancer did not end Joseph's life. After six months of intensive treatment the lymphoma went into remission and his immune system recovered, at least partly. A decade later came the third encounter with death. The toxicity of the ARVs had resulted in acute liver failure and Joseph collapsed. I visited him in the specialist liver unit where he lay dying a few days later. He was so weak that he barely responded to the touch of my hand on his yellow skin. His sister and another friend were there, and we knew that death was imminent. However, within 48 hours, due to a fatal accident, a liver became available, and Joseph underwent a successful transplant operation.

Joseph has a stutter, which increased as he recalled how he suffered physically:

"...I faced my own death. And, and, and...I suffered intensely, physically, not just mentally but I had a very intensive physical suffering both with the cancer and it's treatment, and also with, with, with my, my liver failure. And when I had, had had my liver failure there was no pain control, so there was intense suffering, for weeks, physical pain, day and night, which was unbearable...because it is such a terrible death, it's a slow painful death...when every bodily system begins to shut down, and that...was happening in my case...I had to embrace that reality in order to survive it, if I had fought against it, or if I had gone into denial, I think it would have finished me off sooner. It was because I was resigned and accepting I was able to endure it." (Joseph)

His response to his physical pain reveals how giving way includes the willingness to pick up the necessary cross of suffering. I think it is instructive in regard to the various forms of

suffering that have been described already. In Joseph's case the physical aspect of suffering was equal to his mental anguish. Joseph could pray 'your will be done' only when he stopped "...resisting."

It is necessary to appreciate how Joseph distinguishes between aspects of the 'self'. I have pointed already to the importance of recovering a healthy love of self, in order to survive the affliction of HIV. However, Joseph distinguishes between a true self and a false self which he calls ego. He identifies ego as the locus for human resistance to what is. The ego seeks to defy what must be. Ego insists upon the invulnerable self, and blocks the person from trusting God in dire circumstances. Jesus taught that in order to pick up one's own cross and follow Him required denial of the self.³³² Joseph is very clear, to survive his experience as a person with Christian faith, it was necessary for him to deny this false self; the ego had to stop resisting if he was to give way to God:

"Because, because, because, resistance is ego driven. And suffering when embraced and accepted, breaks down the ego. And the only way out is to accept or to surrender. And ultimately enlightenment and spiritual progress is about surrendering to God...the word ego is 'E G O' for me, is 'Edging God Out', and if you let go of the ego and surrender to God's influence there is going to be enlightenment and spiritual progress. But, as long as we remain in resistance we are actually fighting against God". (Joseph)

Joseph's acceptance of necessary suffering mirrors that of Jesus, first at Gethsemane and later on the Cross. Joseph came to understand his experience of affliction as his way to enlightenment:

"I think that when people suffer enough they become wise and compassionate. A certain compassion and wisdom enters the person...When one really suffers enough, an inner transformation happens. When it is done, when you have embraced suffering in the light of faith, I think it is important to do so in the light of faith. When you suffer and embrace it in the light of faith, enlightenment and wisdom come". (Joseph)

³³² Mk. 8:34; Mt. 16:24; Lk. 9:23

“If you resist then, you remain in your ignorance... in order to gain enlightenment you have to be able to embrace suffering, in the light of faith. But...a state of resistance will prevent or impair progress in the spiritual life”. (Joseph)

Joseph embraced what is, and his experience of suffering changed profoundly. The extreme physical pain that he endured is an obvious point of identification with Christ in His Passion. It was to Christ on the Cross that Joseph directed his gaze and faith drew them closer. He experienced union with Christ. Com-passion: a suffering with Christ and Christ with him through which he was strengthened:

“Embracing is a good word...It is only by becoming one with the pain, or embracing the pain, that one can endure or transcend the pain...So I ended up really, as far as I, I was concerned be-becoming the suffering Christ, I became the suffering Christ. Because...I had to, I had to just accept and embrace the suffering, I became pain itself. I do remember myself saying those words that I, I just wasn’t someone who was suffering I was suffering itself. I just had to embrace the suffering in order to survive it, because the pain was so, so intense...So I became one with the suffering Christ...” (Joseph)

When there was “...nowhere else to go” he found strength in weakness and vulnerable suffering. As he contemplated Christ on the Cross, he was transformed, and his suffering took on meaning.

I began by describing Joseph’s experience as mystical. It is not a word I use often. In my view, it is the meaning which Joseph ascribes to his experience that authenticates his as a sharing in the Passion of Christ and a communion with the Divine mystery called God.

His experience gives an insight into what ‘your will be done’ means within the context of Christian faith. These confrontations with death in affliction made the imperative to love more urgent for Joseph, and again the love of God and love of self are inseparable:

“...the ultimate spiritual issue is Love, and God is Love. What really matters at the end is Love. The love we have for ourselves, for each other, and ultimately for God. So this was the final lesson that really was hammered home when I was dying in intensive care...This was the final message, the ultimate message. Which kept coming through very loud and clear as I lay there during those final, final, possibly final days...I think I always had these underlying values but they became more solid and more concrete as I faced my own death”. (Joseph)

Love was “..hammered home”. Divine love breaks through via crucifixion. When God seemed absent; when human touch was remote Joseph looked to Christ in His Passion and encountered love.

United with the suffering Christ in this way strengthened Joseph, and gave meaning to his suffering. He understood how profoundly loved by God he is because he shared in the suffering of Jesus and felt Christ present in His suffering with him. Joseph’s words may be useful for any Christian living through affliction, not to placate, but as an encouragement to contemplate the God who in Christ participates in our suffering:

“You are the, you are, the suffering Christ, you have to embrace the suffering in order to survive it.” (Joseph)

8.8 Strengthening

In the painful emptiness Joseph’s faith in love persisted; or God’s desire to love persisted in him: “The soul has to go on loving in the emptiness, or at least to go on wanting to love, though it may only be with an infinitesimal part of itself. Then, one day, God will come to show himself to this soul and to reveal the beauty of the world to it..” (Weil, 2009, p.70).

There is a quality of mutuality in his account. A circular breath of giving, reaching, touching, receiving, flows between Joseph and the Divine presence. Love was realized in Joseph and strengthened him.

Recall Luke’s account of the time Jesus spent in prayer at Gethsemane. There we read: ‘An angel appeared and strengthened him’.³³³ The first hearers of Luke’s gospel would have been familiar with the customary preparation of athletes before competition. Before running a long race or about to wrestle, the athlete would receive a vigorous massaging of his muscles with oils. In this understanding the strengthening role of the angel resembles that of a trainer who readies the athlete.³³⁴

Angels appear frequently throughout scripture to encourage and strengthen. Often they announce their presence with the words ‘do not be afraid’. As already noted, angelic figures

³³³ Luke 22:43

³³⁴ Brown, 2008, p.189.

calmed the fears of the women who came, also with oils, to the tomb. They offered reassurance so that in between cross and resurrection the women would not lose hope.

Cate also remembers being visited by an angelic presence. Recall her intense anguish:

"I started crying, and this sound came out of me like a wounded animal...I remember rocking, and crying, from somewhere deep in my soul...a really deep, soul cry." (Cate)

Emotion fills her voice as she tells me what happened next:

"And I felt, what I can only describe as...the wings of an angel that just enfolded me...a warmth, that surrounded me, and held me and it felt like wings. And it just said 'breathe out' and I breathed out and I felt like...enfolded." (Cate)

She felt encouraged, able to go on:

"Enough strength to get up, and get on with the day...although I felt very desolate, but it did feel angelic to me. And that was enough. It didn't matter, and it has never mattered what word I have for the Divine or how I experience that as long as I experience it. So, there, in the absolute desolation after, the morning after, in physical pain, and emotional pain, when I cried out from that deep place I got that warmth and that enfolding." (Cate)

These mystical encounters may resonate with others. However, mystical experiences such as these are rare. More usually the strengthening and encouragement that we receive will come through others. I have described how our subjects had to let go of attitudes and beliefs that hindered them as they faced the temptations to lose faith in God during affliction; and how they had to accept necessary suffering. Jesus was strengthened through prayer before He faced His great trial and crucifixion. His friends took His body from the cross when He had died, and God raised Him to new life. For each person in this study the help of friends would be needed to come down from the cross of HIV.

8.9 Summary

In this chapter I have shown how the initial shock of gethsemane and the terror of crucifixion have given way to a period of adjustment, wherein faith somehow persists. For our participants, this in-between time has entailed a letting go of continued resistance to a

new reality, despite not understanding. For faith, hope and love³³⁵ to survive they had to let go of some Church doctrine and any residual belief in the god of childish imagination. Their giving way to feelings of loss; even feelings of God's absence in the face of death have been occasions of faith-tested and at the same time faith-hope-fully-expressed. In different ways for each person, an important shift in the direction of adult faith and discipleship has begun. Their acceptance of suffering and persistence in faith, are the first necessary moves towards picking up the cross of HIV.

³³⁵ 1 Cor. 13:13.

Chapter 9. Christ with us

9.1 Towards new life in Christ

A brief recap of my argument thus far may be helpful. First, HIV is not 'just a virus', but an exceptional kind of physical illness and spiritual affliction, because of what it negatively signifies in terms of one's understanding of self, others and God. I have also argued that the suffering that attends an HIV diagnosis still today is under-appreciated, because of the normalising of HIV as a medical issue. Being un-encountered in church and society, the significant physical, psychological and social challenges that living with HIV includes are not noticed. The minimisation of HIV related 'stigma' in society constitutes a denial of oppressive forces which remain stubbornly persistent. I have also argued that the meaning of the word 'crucifixion' has lost potency through familiar over-use.³³⁶ I hope to have recovered something of the meaning of both stigma and crucifixion, through the description of my participants' passion experiences.

Secondly, from the evidence of my participants' lives I have argued that the temptation to be scandalised by the affliction of shame, to lose faith in God, and live in shame thereafter is intrinsic to their experience. They have suffered affliction as the scandal of the cross becomes ever more real. As surely as the virus, once out-side the body now lives in each person, so too the scandal of the Cross is internalised and undergone as a passion experience; and as long as the person living with HIV feels themselves to embody scandal, they hang like Jesus, isolated on a cross of shame.

Third, considering the absolute scandal of crucifixion historically, alongside the impact of HIV today, it is clear that the stigma attached to both is relational. It is not a fixed attribute that an individual can be said to have, nor can it be reduced to a description of the prejudices or stigmatizing behaviours within the wider community. It is rather, a negative quality that exists between us and amongst us, which devalues our relationships (Parker &

³³⁶ Above I have argued that the stigma of crucifixion has lost the power to shock. In part because of the 'just a virus' myth, and because of the increased common application of the word stigma to a range of human situations, I contend that the full negative power of the concept of HIV stigma, is similarly diluted.

Aggleton, 2003, p.14). Stigma is not a private matter; it arises within a social context and impacts on both the individual and the wider social body.

This chapter is concerned with those experiences which have helped our subjects in the process of learning to carry the cross of HIV as adult followers of the Risen Christ. It moves in the direction of, or points towards what may be called resurrection experience. In the lives of my subjects, the willingness to carry the cross of HIV is dependent upon a belief and hope in Christ Risen. In Christian faith the notion of carrying one's own cross only makes sense theologically in the light of the Resurrection without which, the capacity to endure suffering or overcome it, remains at the level of human effort to endure imposed circumstance.³³⁷ In the accounts that follow each person moves beyond their passion experience and growth in faith is observable. As they come down from the cross of HIV Christ is encountered in some way. These descriptions do not constitute a neat 'happy ending' to the painful stories that have been told. The marks of stigma will still be seen and heard. However, they contain signs of hope. As will become clear, as the wounds inflicted during the passion of HIV only exist in relation to others so too, healing can only take place relationally.

9.2 Divine 'with-ness'

In his 'Nazareth Manifesto' Sam Wells (2015) articulates an incarnational theology of relationships, with each other and with God, which expands the theological context within which the experience of my subjects can be understood.³³⁸

Wells argues convincingly that it is not mortality but isolation which is the greatest human predicament – our greatest fear is not death, but the fear of being abandoned, of being left totally alone (2015, pp. 35-49). As I have shown in previous chapters, to be diagnosed with HIV is to experience the dread of being 'forsaken'.³³⁹ The isolating impact of HIV is apparent. In the depth of affliction, the enduring social stigma attached to HIV actualises and seems to confirm God's absence. Another way to think of this is as alienation. To embody scandal

³³⁷ Recall Joseph's conviction and emphasis upon the importance of embracing suffering in the light of faith.

³³⁸ Sam Wells is currently Parish Priest of St. Martin in the Fields, Trafalgar Square, and Visiting Professor of Christian Ethics at King's College London.

³³⁹ Matt. 27:46; Mark. 15:34; The experience is also captured in the first verse of Psalm 22: 'My God, my God, why have you forsaken me? Why are you so far from saving me, so far from my cries of anguish?'

means feeling alienated from God, from Christ, from others, and from oneself. It is this feeling of alienation which is so terrifying and has the power to isolate.

From their experiences of passion described already, it is possible to identify four spiritual challenges which must be overcome if these individual Christians are to grow in faith as members of the Body of Christ.

- **In the passion of HIV the divine 'with us' is at risk**

Wells begins his 'Nazareth Manifesto' (2015) in the following way: "God is with us. These four words express the character of God, the identity of Jesus, the work of the Spirit. They are the Christian testimony about the past, witness in the present, and hope for the future." (p.7). He argues that the single most important word in theology is 'with', and that this little word is at the heart of Christian faith. (p.11). "With is the key to the identity of who God is." (p.8). 'With' describes God's commitment to always be *with us*, and the "...incarnation is the epitome of with; together with the resurrection, it is the epistemological center of a theology conceived around the notion of with." (p.232). Jesus exemplifies God's promise at the cost of His own life. God's commitment to be with us whatever the cost, and under all conditions, and through every affliction, is demonstrated through Christ on the Cross, where even the connection between Father and Son – the 'with' at the heart of the Trinity - is momentarily risked. (p.81). In terms of faith, each of my interviewees has been most deeply scandalised when God's love seems remote, and the promises of Jesus the Saviour appear meaningless. For my participants it is this divine relational quality of 'with-ness' that is in jeopardy, the apparent loss of which creates a crisis of meaning, belonging and faith. It is the existential crisis provoked by the threat of the most profound isolation. God's promise embodied in Jesus the Christ – 'the Word made flesh'³⁴⁰ - and continued through the Spirit,³⁴¹ to remain with us in everything, is at stake.

- **The spoiled identity of the stigmatized other is first learned within the community of faith**

As the stigma of the Cross and Crucifixion was mediated culturally and religiously, so too HIV stigma exists in both society and the Church today. Each of the people in this study

³⁴⁰ John 1:14

³⁴¹ John 14:16;26

interiorized subtle and more overt 'messages' relayed to them, about what HIV signifies and means in terms of their acceptability before God and others in the Body of Christ. The negative spiritual and theological implications of an HIV diagnosis were first learned within the church and their own community of belonging.³⁴²

- **The stigma of the cross imposes isolation via silence**

The main barrier to be overcome is that of the silence first imposed by fear in the gethsemane of diagnosis. Without the opportunity to communicate one's reality, HIV can only ever remain a painful, shameful secret. Without sharing their confusion, grief, anxiety, distress and pain, the person cannot be open to the experience of loving acceptance as they are. After diagnosis, a person who is not known to be living with HIV by at least one other person can never be reassured of their acceptability or love-ability, because they will not be known for the person they have become: a new kind of person shaped inevitably and irrevocably by HIV.

- **The passion of HIV is re-membered in the Body of Christ**

Even if we can imagine a time in the future, when the virus could be erased from the body, the fact of living with HIV is still, and would always be, re-membered in the person. As I have argued by definition the experience of affliction is never forgotten. As surely as the wounds inflicted upon Jesus on the Cross were re-membered in the body of the Risen Christ, so too the passion of HIV once undergone, is always remembered bodily. Taking St. Paul seriously then,³⁴³ it follows that when any Christian is diagnosed with HIV, although it may be hidden from the view of others, the passion of Christ living with HIV is re-membered within the community of faith called Church.

Leaving to one side the wider ecclesiological implications of these four points, the question then becomes one of how HIV is carried in the body, soul and mind of the person; and how, in the context of damaged and damaging relationships, might faith be restored. How will the silence be broken? Can the spoiled identity give way to dignity? Can the wounds heal even

³⁴² The negative judgments about the person which are derived from doctrine, preaching, and ecclesial culture are 'complimented' by the influence of other communities of belonging which include, for example, the family, peer group and other social milieux.

³⁴³ 1 Cor. 12:12-27

though they remain as a kind of stigmata, in the form of scars; or will they stay open and raw, always sore to the touch?

As we heard above from Cate and Joseph, the necessary naming of what is painful often begins privately, with a desperate and hopeful appeal to God. In their time of alienation and isolation they reached, in distinct ways, for a sense of re-connection with the Divine presence, and they were reassured through powerful experiences of Divine 'with-ness'. I have called this 'mystical'.

Like affliction, these experiences are never forgotten, because of their profound affect. The solitary dimension is important to notice. However, in this solitary place they no longer felt so totally alone. As Joseph put it:

"One must walk this road alone. No-one else can...walk it with you. The road of suffering and ultimately death, one walks this road alone. Except, of course God is there with you, but he is the only one." (Joseph)

Their awareness of God-with them changed everything. In the felt-presence of the Spirit the 'Divine-with' is experienced and Cate and Joseph knew that they were not alone. What had seemed utterly unendurable became sufferable.

9.3 Discovering divine with-ness through prayer and in community

A recovery of the sense of the 'divine-with-us'³⁴⁴ in the place of isolation is necessary if the Christian living with HIV is to move through their gethsemane and golgotha towards new life in Christ – towards resurrection. The wings of an angel conveyed God's embrace to Cate, and Joseph felt united with Christ in his suffering, but the depth of God's love is more usually embodied in human touch. In what follows the reader will see how the personal-intimate dialogue with the Divine, the being-with God which is prayer, combines with the

³⁴⁴ Here I choose not to capitalize 'divine' deliberately. The state or awareness of divine with-ness that I am describing belongs not solely to God as a type of one-sided move from God towards us as benevolent gesture from the all-powerful God to the suffering person. The spiritual 'shift' that takes place for my interviewees is more than this. It is rather, a deepening awareness of the mystery-reality of what God-with-us means: it is not a passive reception of something new, but a deepening realisation of that which already exists between us and God. It is to believe Jesus' promise to His disciples in John's gospel when He said 'I will not leave you orphans' (Jn. 14:18), and Jesus promise that where two or three meet in His name, He is there among them (Matt. 18:20 NJB translation). It is to begin to understand that God's invitation through Christ in the Spirit is to share in the life of the Trinity. It is to enter into the intimacy of divine with-ness: 'Because I live, you also will live...I am in My father, and you are in Me, and I am in you.' Jn. 14:19-20.

being-with-others, in the process of healing and strengthening. Again, this is not a linear process, both the private-intimate and the social-ecclesial aspects of 'God-with-us' are intertwined.

As Martin put it, for wounds to heal *"Time, and prayer and other people"* are needed. Recall how, despite suicidal thoughts, he clung desperately to what hope he could muster. It is as though he insisted that God must still be with him somehow, and he persevered in prayer.³⁴⁵ In the midst of doubt his faith was the well from which he drew so that he could live in the hope of a better time.³⁴⁶ Martin, who had equated God-with-him as feeling safe, was at his most vulnerable, without a sense of safety. However, this vulnerability opened a way to a deeper level of divine with-ness.

"...there was a complete sense that I had absolutely connected to God...in a way that I didn't understand or hadn't experienced before...in a way I didn't want to experience. There was a lot of anger...I was angry, and wanted to abandon God, but also relied on God."

Around this time, Martin had to face his alcohol addiction. He tells me that it was not the events of leaving the seminary, or home, or his diagnosis that caused the addiction but *"...alcoholism affected me...more severely than it might otherwise...those experiences all culminated in being unable to cope and that sense of abandonment."* (Martin)

Each person in this study spoke about how the support they needed was not available within their local parish church.³⁴⁷ Martin was no exception. It is not coincidental that he scrutinized the parish so closely. He was trying to stay connected to God through the Church, but once again the challenge was how to explore his faith with other Christians, when he did not feel safe enough to be open about himself and his differentness. Especially now that he had a significant HIV positive difference, which set him apart.

³⁴⁵ 'Consider it pure joy, my brothers and sisters, whenever you face trials of many kinds, because you know that the testing of your faith produces perseverance. Let perseverance finish its work so that you may be mature and complete, not lacking anything.' James 1:2-4

³⁴⁶ 'We were given this hope when we were saved. (If we already have something, we don't need to hope for it. But if we look forward to something we don't yet have, we must wait patiently and confidently.' Romans 8:24-25 (NLT).

³⁴⁷ This is consistent with the research reported in chapters one and two where a majority of Christians living with HIV said that they had either not revealed their HIV status to members of their faith community or had not felt supported when they did.

"I was not finding what I needed in terms of God and faith in a normal Catholic parish community...I heard...that the Gospel was about being inclusive...what I saw was exclusivity...it didn't feel like a place where I could reveal who I was as a person.." (Martin)

What then was Martin's way to recover his sense of 'absolute connection' with God? He attended Alcoholics Anonymous (AA) groups, and he *"...very quickly went through the twelve step program...which is about helping a person find God and their relationship with God."* He also sought understanding from his house-mates. His sharing had unexpected outcomes. Two others revealed they were also living with HIV. One of the friends had kept the secret that isolated him from anyone close for several years but *"...he decided it was ok to tell the rest of us...in that way, it turned out to be a positive experience.." (Martin)*

Martin's courage and vulnerability began a process of healing, not only for himself but for others. Through friendship and shared experience the silence which isolates is broken. However, he was aware of his need for specifically Christian fellowship and support.

"I can't be a Christian all by myself. Not something that can be done isolated or all alone, it needs to be done in community." (Martin)

He made his way to a Positive Catholics peer support group meeting, and there he found *"Christian community...a community of people, on the margins, who have similar experiences...who help each other to find God..." (Martin)*

The angelic message 'do not be afraid' was embodied in the group:

"...people weren't afraid to talk about God, weren't afraid to talk about being gay or living with HIV. And immediately it felt like, safe and comfortable, and a place where I could work things out for myself." (Martin)

I want to notice how over time, Martin's awareness of divine with-ness came through personal prayer mediated via the embodied love received from others.

"I have found...two loving, caring, Gospel communities one clearly in name, and one not so much...I have had the opportunity to feel loved, feel welcomed, to, to be given the time and the space to come to know who I am, to accept myself.."

The acceptance and welcome that he received in both AA and Positive Catholics sustained him. As he reflected upon his experience and shared himself with others, he recovered a sense of trust in God:

"..out of those experiences...my idea of God changed. It was there that God felt real and present and tangible....as I was changing...the experiences of God were, motivating me and were grounding me. And there was a sense that everything would be ok, and everything would be safe and it would be fine. And these experiences weren't these blinding light experiences. I had a sense that God was there...an understanding, a sense that everything is ok."

The understanding of Christian faith as a journey is well known. That there are stages of physical, psychological and emotional development in the human journey from childhood to maturity, is also well known. In a similar way, there are observable stages in one's journey in faith.³⁴⁸ Through all his experience, Martin's faith has developed into a more 'adult faith'. St. Paul wrote in terms of leaving the things of childhood behind as the Christian matures in faith.³⁴⁹ This maturing in faith is also equated with 'discipleship', and comes via an acceptance of the necessary personal cross that, Jesus said, those who would follow Him, must pick up.³⁵⁰

Intrinsic to discipleship is service. This desire to serve others is the last necessary 'spiritual ingredient' which I want to make explicit in Martin's story. The acceptance and welcome from others enabled Martin to make faith-sense of painful experience, and through lovingly serving others, after the manner of Jesus, he enters further into the mystery of divine-with-ness:

"...helping other people, (that) is where I come to a more fuller understanding of, of myself, and my connection to God, and my purpose...it's been in Positive Catholics...helping other

³⁴⁸ I am using the term 'stages' in a very broad sense. As I have repeated throughout this thesis the way in which one's journey in faith proceeds is not necessarily 'linear' or as clear cut and definable as the term 'stages' might imply. My main point is simply to recognise that Christian faith necessarily develops (or not) as we mature as human beings and is linked to experience. See for example Fowler, 1995; Slee, 2004.

³⁴⁹ 1 Cor. 13:11

³⁵⁰ Mk. 8:34; Matt. 16:24; Lk. 9:23

people to come to terms with their HIV status and their faith and their connection to their Christian community that has made the real difference really.” (Martin)

I have paid attention to Martin’s descent from the cross of HIV; his healing in community; and the strengthening of his faith, because his story illustrates what is meant by the phrase ‘new life in the risen Christ’; how the divine-with became real for Martin.³⁵¹

A similar journey through the passion of HIV into new life was shared with me by others. Everyone spoke of the importance of personal prayer.

“My prayer has increased...prayer keeps me going.” (Rosie)

As with Martin, the place of vulnerable isolation became the site of perseverance in faith.

“My relationship with God changed...I became more aware, more reflective, and more in prayer, to seek spiritual support through prayer...We can always turn to God to find some way of healing...So that would strengthen me to move on..” (Piramo)

In personal prayer Francis recognised a spiritual vulnerability.

“..increasingly since diagnosis I have been more reflective about the fact that our spirituality finds it’s expression only through our physicality and our bodies. And if our bodies are sick then our spirituality is finding it’s expression through our sick bodies as well..” (Francis)

Again, the point is reinforced, that the isolating silence must be broken for healing to begin. But as with others, Francis found that in those places where he could speak of his HIV, the medical clinic or gay men’s support group, his faith was not understood, and to speak of HIV in Church seemed impossible.

What was inaccessible in the parish they received within Positive Catholics.³⁵² Their doubts and fears, pain and hope, could be honestly shared within this ‘fellowship of the weak’³⁵³ without judgment or rejection. The combination of shared prayer and the experience of embodied love had a healing affect for Lazarus:

³⁵¹ ‘Therefore, if anyone is in Christ, the new creation has come: The old has gone, the new is here!’ (2 Cor. 5:17).

³⁵² Paul is the exception. He has never attended a Positive Catholics group.

³⁵³ I first came across this phrase in Henri Nouwen’s (2006) reflections, drawn in large part from his experience of the L’Arche community where people with and without learning disabilities live together.

"The first time I attended the Positive Catholics Retreat weekend...It clarified to me, the meaning of 'Healing'. A lot of people will take 'Healing' as the removal of disease and making somebody whole and complete. It is a different perspective, where there is acceptance of what one is...and you are unwell, but, you come to accept that in the eyes of God, you are all His children, and you all fall under His Grace. It takes the burden of guilt off you. It makes you want to hold your head up high in church. That God will accept you as you are, and not judge you, as man does." (Lazarus)

Rosie and Tiago both spoke of how belonging to Positive Catholics and sharing their experience in the light of faith with others who understood, because they too had carried the cross of HIV, was liberating and healing. What was inaccessible within the clinical setting or the secular support group, was available through this HIV positive community of faith.

"..healing came through Positive Catholics...meeting people who were having the same problem. Not feeling isolated with that. Not only talking with people who was gay and positive, but with people who are positive and have a faith, which is different...I was open, to see HIV and Aids from different perspective. Now, us, HIV positive...it was a awakening for me, of, of what to do." (Tiago)

"I can come and talk about my faith and talk about my HIV too, it is just like two things in one...It has helped me living with my HIV...(and) make new friends. I feel at home. Sometimes I cry, to let go. I would encourage, all the faith people to come to the group. We all learn." (Rosie)

Joseph also names that desire to love and serve others as a necessary spiritual ingredient for healing and strengthening to begin. In the willingness to be-with others, he sees a sign of new life that comes after the affliction of the cross; he recognises the Risen Christ where there is both love and service, not despite the cross, but because of it.

"Since becoming involved with Positive Catholics I have seen a greater degree of compassion and acceptance, and non-judgementalism...because they have been touched by suffering and that seems to bring about a, an inner transformation. I have had more experience of the compassion of Christ through my contact with Positive Catholics." (Joseph)

And Rosie speaks of new life in a way that reminds me of that most visceral confrontation with fear, when she says, simply:

“And if you meet people also who lived with HIV for a little while and they also talk about it, I can say, come on I can live for fifty years more!” (Rosie)

9.4 Recognising Christ Risen

After Jesus had died, and before they believed that He had risen, the disciples were afraid.³⁵⁴ Those closest to Jesus gathered together in a closed room, a place of safety, where they hid.³⁵⁵ Two others on the road to Emmaus walked away from the site of crucifixion, disconsolate and crest-fallen.³⁵⁶ The scandal of the Cross had extinguished their hope.

In the upper room Christ appeared to his friends and said ‘Peace be with you’, and he showed his wounds and asked Thomas to touch him.³⁵⁷ He did not appear to them in a perfect unblemished body but revealed the signs of His suffering so that they would believe. And Thomas exclaimed ‘my Lord and my God’.³⁵⁸

On the road to Emmaus a stranger joined the two disciples, and they were astonished that he seemed unaware of the scandalous events of the weekend. ‘Have you not heard’ they asked him. But he stayed with them and listened to their experience and all that they had witnessed and found so distressing. Then he interpreted all that they had told him in a new way, in the light of their Scripture, according to their faith; and ‘their hearts burned within them’ as he spoke. When the evening drew in they insisted that the stranger stay with them. And as they ate together, and when He broke bread, they recognized him.³⁵⁹ It was Christ himself who had accompanied them.

The disciples encountered Christ-risen in new and unexpected ways.

Amidst fear and disconsolation, the people in this study persisted in prayer. Despite all indications to the contrary their faith, and their vulnerability, compelled them to trust that somehow God remained with them. Often in hiding, the silence imposed upon them was first broken in personal prayer as their anguished cries named their pain. They enacted their

³⁵⁴ This very brief summary of Jesus’ appearance to the male disciples is a simplified composite of the Gospel accounts. I have referred earlier in this thesis to Jesus’ appearance to the women, who did not share the same disbelief of the male disciples. See footnotes 300, 317, and chapter eight.

³⁵⁵ Mk. 16:10-11; Jn. 20:19

³⁵⁶ Lk. 24:13-18

³⁵⁷ Lk. 24:36-40; Jn. 20: 20-27

³⁵⁸ Jn. 20:28

³⁵⁹ Lk. 24: 15-32

belief in God, and if only as an ember of faith and hope, in prayer their sense of divine withness was sustained.

Like the disciples they too gathered with others in a safe place. The understanding and acceptance that they received from Christians also living with HIV soothed wounds so sore to the touch. Healing began when they were able to show the marks of the passion of HIV in their bodies to others. Sharing their experience in the light of Scripture with others, and praying together, and breaking bread together, their sisters and brothers revealed the scars in their bodies to them, so that they might believe in new life. The promise Jesus made to continue to be with them actualized as the Body of Christ re-membered among them. The divine-with embodied in the Crucified and Risen Christ encountered in this fellowship of the weak.

9.5 Summary

In this chapter I have shown how my participants began to heal the wounds of shameful indignity that they came to embody under the curse and scandal of the cross. I have situated their experience within the broader theological framework of divine-withness, and argued that as the sense of God with us is lost when the person embodies scandal it is this relationship which needs restoration for healing to take place. I have shown how my subjects began to break free from isolating silence in prayer, and how their liberation from fear began when they summoned the courage to be seen and heard in their vulnerability, with others. I have argued that it is through the acceptance and understanding of others that divine-withness is actually restored. These necessary moves from silence and isolation, towards vulnerable sharing can be understood as the actions of adult Christian's who have begun to carry their cross of HIV. I have argued that as Christians living with HIV enact faith in these ways; as the Christ who reveals sore wounds is received and accepted by the Christ who bears the scars of similar experience, Christ Risen with HIV is re-membered in mutual encounter. God's healing power and presence is evident above all in those communities where Christ is embodied in the practices of love (McDonagh, 2007, p. 46).

Chapter 10. Summary & Conclusion

10.1. Introduction

In this concluding chapter I will present a summary of what I have presented in this study, and the arguments I have made. In my introductory chapter I explained how my argument, that the lived experience of HIV in the body of Christ can be understood as a type of passion experience, that is, as a privileged sharing in the Passion of Christ, would be presented via a series of encounters. In this thesis I have intended to make present for the reader, the historical and contemporary experience of others, which I have argued is either forgotten or unseen and unheard, in such a way as to effect some change in the reader. Recall my main aims from the first chapter: to produce a study that will be of pastoral and spiritual encouragement for any person living with HIV; and to inspire in any Christian who reads this a deeper consideration of and reflection upon what it means when we say that the body of Christ is living with HIV today. Through the portrayal of real people and a series of encounters with their experience, I have, to put it simply, tried to bring into view a lived-reality with theological significance so that the reader will see, hear and understand in fresh ways.

In my own experience, and as described through the stories of others, one test of the significance of any encounter is the extent to which it is remembered. It is evident that the encounters and experiences that are remembered bodily, shape one's identity, and therefore also exist within the social bodies to which we belong. The encounters which carry most meaning for a person effect a change in the person and affect all their relationships. Whether a painful experience or a graced encounter; falling in love with another person or feeling abandoned and betrayed; encounters that stay with us are those that have left a mark on our soul and often in our bodies.

And, as is evident in Part II, just as the encounter with HIV for each of my principal subjects has raised questions, any meaningful encounter will raise new questions. Having revisited the argument and content presented, through a summary of the two parts of this study, I will conclude with some thoughts related to the ways in which I understand the Passion of Christ as presented in this study to be pastorally helpful, and how this study relates to the universal Church and the whole Body of Christ in the world.

10.2 This study in context

In the first part of this study I have paid attention to the questions of why this study is needed; I have explained my own motivations for undertaking this inquiry, and described the ways in which I have navigated the research process; and I have described the phenomenon of HIV historically and factually within wider society and the Church. Taken as a whole, Part I provides sufficient information so that the theological argument made in Part II is credible. Situating HIV and Aids as a phenomenon in society and in the body of Christ historically and providing an up to date account of the medical, social and pastoral realities for people living with HIV in this country today, contextualises this study.

In my introduction and continuing in chapter two I have provided the first historical account of the Church's responses to HIV in this country. It is by no means a total history or full account, but is a potential source for future study. At a time when there is renewed interest in various aspects of the history of HIV and Aids, not least within academia, I think it important that how Christians have contributed both in the past and the present in positive ways is not wholly forgotten. I have traced both the theological and pastoral responses to HIV. There I argued that as a whole the Church was rather slow to respond to HIV in our midst, but individual Christians were actively involved as committed volunteers from the very earliest days of HIV and Aids, and later a number of charitable groups with Christian aims provided significant pastoral support for people infected and affected throughout the country. As I argued in the introduction, giving some account of those who have devoted themselves to 'being with' others in this particular site of suffering, is also to meet an obligation to keep alive the memory of their struggle and Christian witness. I also argued that the introduction of successful treatment in the West, and the growing awareness of the global scale of the pandemic lead eventually to HIV and Aids being thought of once more, as something distant and remote. In chapter two I showed how the theological focus shifted away from HIV as a matter of individual sexual morality and more towards HIV and Aids as a 'sign of the times' which reveals dimensions of structural sin and social injustice that called for a global response.

This shift in attention to HIV and Aids as a matter of international development resulted in a parallel lack of attention to people living with HIV in our midst. I have shown that whilst people living with HIV in this country remain amongst the most marginalised and

disadvantaged 'poor' amongst us they are effectively ignored within the Church today. That, I have argued, justifies this study.

Also in Part I, my interviews with theologians described the broad theological terrain within which this study sits. There I also provided the last recorded interview with Sebastian Moore and to my knowledge the last with Kevin Kelly, both of whom have since died. A number of these interviews also showed the ways in which the encounter with HIV, for these theologians has been a 'graced encounter'. Again, these accounts are of value as a source for further research and make an original contribution to academic debate.

In the last chapter of Part I the Christians living with HIV who are at the heart of this study, have been introduced to the reader. In both of the interview chapters I presented these accounts in quite a full way, in a style and length more usually found within an anthropological or narrative research study. I have argued that this is justifiable given the paucity of first person accounts of what living with HIV means for Christians today. I wish to present as fully as possible, their own reflections and theological interpretations. Secondly, I intended to allow the reader the possibility of encountering each of these people in their own words. Again, these interviews may also be of use to others undertaking further research.

In summary, attempting to explore the question of what it means when we say that the body of Christ is living with HIV in this country today, I have contextualised HIV in Part I and argued that:

- Although people diagnosed are not facing Aids and death as an inevitability today, HIV infection is a long term condition which increases vulnerability to physical and psychological ill health
- HIV status coincides with other disadvantages; HIV impacts disproportionately within groups who are already marginalised because of low social status, ethnicity, poverty, immigration issues and gay sexuality
- Incidences of poverty, mental illness, social isolation, and comorbidity are significantly higher for people living with HIV when compared with the general population

- Christians are challenged and divisions in the church are exposed by HIV in the body of Christ – especially along the moral fault lines of sex and sexuality
- Theological and ecclesiological issues amplified by the forced encounter with HIV and Aids in the eighties persist today. Christians in the mainstream churches in this country, both then and now, assert that the Christian principle of compassion and care should always be shown to those who suffer and after the manner of Jesus have a special duty to be aligned with those who are marginalised in society. However, this Gospel stance lacks credibility in view of the internal ecclesial tensions between the twin doctrinal imperatives of offering compassionate care, and maintaining sexual orthodoxy, that are communicated in word and action in response to the HIV pandemic, both then and now.
- Christians living with HIV are generally unseen and unheard, hidden from view, effectively excluded from full participation in the Church
- The Church is failing to provide adequate pastoral provision for those people living with HIV in our midst who have asked for acceptance, guidance and healing, but continue to feel ignored
- A lack of encounter between those diagnosed with HIV and members of the church results in a lack of awareness within the wider body of Christ
- Therefore, whatever HIV in the body of Christ means, theologically, cannot be discerned within the Church – were the question posed by Jesus through the judgment parable in Matthew's Gospel asked of most Christians today, the only possible answer would surely be 'but when did we see you living with HIV'?

With my introductory chapter the evidence presented in Part I and the arguments made provide the broader historical, social, epidemiological, medical, ecclesial, pastoral and theological context for this study. Taken as a whole Part I sets the scene for the more focussed theological argument in Part II.

10.3 Encountering the Passion of Christ living with HIV

The lack of visibility of our sisters and brothers living with HIV in the Church has merited my attention to the faith-sense made of living with HIV by my interviewees in the second part of

this study. In Part II my argument that living with HIV today may be understood as a type of passion experience has been made.

I began in chapter six by exposing the 'just a virus' and 'guilt and innocence' narratives that are both pastorally insensitive and I argued, if unnoticed, act as barriers to understanding the phenomenon of and embodied encounter with HIV. In chapter seven I related the experience of diagnosis to the confusion and shock that the disciples felt in the garden of Gethsemane. Drawing from Simone Weil I argued that the suffering which each of my interviewees underwent can be understood as affliction, within which the psychological, physical, social and spiritual dimensions of suffering are combined. Affliction compels a person to recognise as real what was thought impossible, and is re-membered in the body. I argued that the reality of an HIV diagnosis is similar to the affliction that Jesus underwent in His Passion. I also introduced the sense of being scandalised by Jesus that the disciples felt, and related that to my subjects' feelings of being let down by God. Through my description of HIV as a gethsemane experience, I argued that being scandalised by the fear of abandonment to public shame is the first shocking identification with the scandal of the cross. I argued that the fear and trauma deepens as the person living with HIV internalises the stigma of the cross of HIV and comes to realise that they personify and embody that scandal, as Jesus embodied scandal on the Cross.

In chapter eight I argued that the adjustment to life with HIV after the intensity of their passion experience requires a 'letting go' and a 'giving way'. For faith, hope and love to survive each person had to let go of some Church doctrine and any residual belief in the god who is capable of withdrawing Love. Their giving way to feelings of loss; even feelings of God's absence in the face of death have been occasions of faith-tested and at the same time faith-hope-fully-expressed. I argued that this represents an important shift in the direction of a more mature faith, and that acceptance of suffering and persistence in faith, are the first necessary moves towards picking up the cross of HIV. I have argued that the scandal of abandonment to shame on the cross of HIV and feeling abandoned by God and others is an experience of intense isolation. For faith to be sustained and healing to begin, the 'divine-with' that sustains people of faith at sites of suffering needed to be experienced again.

In chapter nine I have argued that to begin to pick up the cross of HIV and follow Jesus as His disciples requires prayer and the support of Christian community. I provided examples of

how the being-with God which is prayer combines with the being-with-others, which is communion, so that a process of healing and strengthening may begin. I have begun to show how the pattern of God's Kingdom is "...glimpsed in the lives of vital communities of faith...who know and practice the empowering ways of the cross and resurrection and are engaged in the work of life and death, liberation and reconciliation" (Thornton, 2002, p.23). The memory of the Passion of Christ is thus kept alive within this fellowship of the weak who have shared their wounds with each other, and by so doing, the Body of Christ Risen with HIV is re-membered in mutual loving encounter.

In the introduction, I argued that this study has the potential to be healing or liberating for any person living with or directly affected by HIV if even a slight shift in the way they view their experience occurs. My argument in Part II has proceeded with this pastoral outcome in mind, so that living with HIV as a Christian may be perceived in a new way. To name my interviewees' experience as sharing in the Passion of Christ offers a dignity to suffering that is more often disregarded. In this way this study is presented as a practice of compassionate solidarity with others.

Consistent with the methodological approach argued for in chapter three, I have made my arguments in order that theological meaning is revealed. I have presented this research trusting that fresh insight can arise through the various types of encounter in each of my chapters. The study is consciously structured to deepen understanding both affectively and cognitively. That is, to touch the heart as well as the intellect of the reader. It is my hope that through this study new insights and questions have been prompted.

With faith I hope that any person who has been diagnosed with HIV will feel strengthened and affirmed through this theological reading of living with HIV as a type of privileged encounter with Christ. I have argued that through my participants' experience it is possible to encounter the Christ and Christa in painful disguise today. The Christ who suffers, is crucified and risen, may be recognised, seen and heard, through the people living with HIV in this study.

10.4 Concluding reflections: The Passion of Christ living with HIV

Bryan Massingale (2009) writes: "It is difficult to approach this topic with fresh eyes and new enthusiasm. In this, the third decade of the pandemic of HIV/AIDS, what can be said

that has not already been said?” He cites issues relating to HIV in a North American context: The disproportionate impact of HIV within BAME communities and particularly within African American communities; the effects of lack of access to health care and needed medical sources; “the pervasive stigma and discrimination thrust upon and endured by those living with HIV infection; the compassion fatigue and widespread indifference that mark the responses of many to the horror that unfolds around us.” He reflects on the fact that he discussed all of these aspects of HIV in a presentation to the Catholic Theological Society of America nine years earlier. He argued then, that “an American public theology cannot be ‘attentive, intelligent, reasonable, and responsible’ without coming to grips with the ominous threat that HIV/AIDS poses to the survival of communities of color.” He continues: “Depressingly, much of that previous work could be repeated now, only with exclamation points!”³⁶⁰

I can relate to Massingale’s exasperation. When I began this research, I shared his sense that much had already been said and written about HIV and Aids as a sign of the times deserving urgent theological attention. This study raises a wide range of social issues and many of the challenges for the Church have been stated again. However, I had a hunch that to repeat a list of social injustices as an appeal to charity; or deconstruct the anti-Christian HIV stigma manifested through the prejudices and discriminatory practices of homophobia, sexism, patriarchy, racism, colonialism, and xenophobia; or revisit the bad habits of Christian tradition that link sex, sexuality, disease and sin; as examples, would not reveal the meaning of HIV today through ‘fresh eyes’. I have referred to these issues, and some of the theologians who have raised them, directly and indirectly in this thesis. The theological landscape of HIV and Aids is vast. I trust that the reader will have made many of these connections whilst paying attention to the lived experience of my interviewees who have shared their faith with us in this study. Again, so many of these topics, remain open for further theological inquiry; as Julie Clague said in my interview with her, I think we have only

³⁶⁰ Masingale is a Roman Catholic priest and Professor of Theological and Social Ethics, Fordham University. He is a past Convener of the Black Catholic Theological Symposium and a former president of the Catholic Theological Society of America.

begun to scratch the surface, theologically, of what God wants us to see, hear and respond to meaningfully, through Christ embodied and living with HIV in our midst.

Rather my approach to inquiry has drawn upon the lived experience of Christians with HIV. I have brought something of their 'underground theology' into view. There is more that could be learned from a closer study of the practices of faith within the Positive Catholics community. Nevertheless, in chapter nine and elsewhere, I have begun to show that healing and strengthening may be actualised through the solidarity of the body of Christ in a fellowship of the weak. I hope that in this study, HIV is encountered with theologically fresh eyes and new enthusiasm.

I hope to have shown, especially for anyone living with HIV that through His Passion and Cross Jesus embraces and proleptically unites the real suffering bodies of people living with HIV to His own.³⁶¹ His embrace neither diminishes nor negates the affliction suffered but allows painful experience to be understood in new ways. The passion of HIV may be accepted when one contemplates the affliction of Jesus: rejected, stigmatised, judged, condemned and crucified in the ultimate act of divine-solidarity-with humanity for all time. Suffering undergone may be dignified through faith in Christ who reveals power and meaning through God's saving action of compassion.

The Kingdom of God is actualised as a companionship of empowerment and practices of compassion, welcome and solidarity (O'Murchu, 2015).³⁶² To believe the greatest sign of God's love for us is embodied on the Cross; and have faith in Christ who has undergone all human suffering, becomes saving praxis when wounds are touched and Resurrection hope is restored within a community of faith. For the sister and brother living with HIV, this healing, liberating, and strengthening may be encountered within the body of Christ living with HIV.

10.5 Concluding reflections: the universal body of Christ living with HIV

The encounter with HIV in this study is not just about those living with HIV in the domestic Church. This is also for the marginalised and discarded (EG 195) people living with HIV in the

³⁶¹ Drawing upon Copeland (2010, pp.5-6). I understand 'proleptically' soteriologically, as meaning that which is anticipated in human history and already and presently achieved in the divine economy of 'God's time'.

³⁶² O'Murchu argues that the most likely Aramaic word for 'Kingdom' as in 'the Kingdom of God', used by Jesus was *malkuta*, which may be translated as the companionship of empowerment. (O'Murchu, 2015, p.53)

USA, and around the world. Adriaan van Klinken (2012) picks up the observation of Emmanuel Katongole who comments critically that “metaphorically Western churches are yet to be infected by HIV and AIDS...churches in the Western world at best respond with charity towards AIDS in Africa (the Church as an NGO), and are not really affected by the suffering of their Church to realize that they are part of the universal body of Christ with AIDS, and to be in solidarity with those faced with HIV and AIDS directly.” Elsewhere van Klinken (2010) explains that “...the churches in the west tend to view the HIV epidemic as an African problem, and therefore remain silent about it” and he recognises that “it is somewhat difficult to expect Western churches to identify as the body of Christ with AIDS...HIV occurs there as well, but only on a small scale and it is relatively under control. This explains why the epidemic has not been an urgent issue for Western theology.”³⁶³

The ‘exclamation marks’ above from Massingale, and van Klinken’s (2010) challenge to Christians in the West to “imagine their suffering affecting our own lives” are surely appeals for solidarity and action on the part of the whole Church. At a basic level, they echo my argument that people living with HIV deserve to be seen and heard. They confirm my argument that Christians living with HIV remain largely unnoticed and ignored. They accuse the Church and theology of not having understood what HIV means in the body of Christ.

Whilst the Church is actively contributing to the needs of people affected by HIV in poorer countries, it should disturb us that the spiritual, pastoral and actual needs of people living with HIV here are routinely neglected. That a woman living with HIV may be provided with clinical care at a Christian medical facility in Kampala is obviously a good thing. However, that her sister living with HIV sits alone in a church in Manchester, unseen and unheard, or that her gay brother living with HIV in London or New York remains excluded, should surely disturb us.

As I have argued throughout, to reduce HIV and Aids to a medical condition needing a clinical response, is to overlook the pastoral and spiritual needs of people living with HIV. I argue that this is true whether that occurs here in the UK, in the USA or in Africa. In this study, in solidarity with Christians living with HIV and Aids everywhere, I am arguing that the

³⁶³ Adriaan van Klinken is Associate Professor of Religion and African Studies University of Leeds.

challenge for Christians in the West and for theology is not to 'imagine that HIV affects us' but to act more authentically because the body of Christ is living and dying with HIV.

The Christian duty of hearing the cry of the poor is incarnate in the body of Christ only when we are deeply moved by the suffering of others (EG 193) and this cannot happen without honest encounter. The "Gospel tells us constantly to run the risk of a face-to-face encounter with others, with their physical presence which challenges us, with their pain and their pleas, with their joy which infects us in our close and continuous interaction" (EG 88). We are invited again to receive the loving embrace of Christ crucified and risen, not only in the bodies of women and men living with HIV, but in the bodies of all those who are neglected, cast aside and rejected. Because they embody Christ in our midst, crucified and risen, today.

Paying attention to the lived experience of my interviewees opens a way to encounter the neglected Christ living with HIV in the Church. I have argued that investigating what HIV means for the body of Christ today may challenge the wider church to respond in more authentically Christian ways, and, after years of reflection, there is wisdom and insight that our sisters and brothers living with HIV have to offer the wider Church.

Appendix 1.

St Mary's
University College
Twickenham
London



RESEARCH PARTICIPANT INFORMATION SHEET – People living with Hiv

Section A: The Research Project.

1. What does it mean to be the 'Body of Christ' living with Hiv/Aids?
2. This study aims to identify theologically significant aspects of the Hiv pandemic in the UK. I hope to 'amplify' the voice of people living with Hiv, who also identify with the Catholic Church in some way. I intend to bring the lived experience of Hiv into dialogue with Christian tradition, Scripture and pastoral practice. I hope to discover aspects of Hiv as lived out in a Christian context today, which may be helpful to those infected and/or affected, and may also inform the wider Church, theologically and practically.
3. Research is supervised and funded through St Marys University College. It may be used towards the publication of articles, the presentation of papers at academic or other conferences and eventually towards a published PhD Thesis.
4. You are asked to agree to a recorded conversation with me, Vincent Manning, which will be used primarily to assist my own thinking, and theological reflection; to inform further research; and may possibly be used publicly in the future, (e.g quoted and attributed as part of my PhD Thesis).

Section B: Your Participation in the Research Project

1. As a person living with Hiv who identifies as a Christian within the Catholic tradition, presently or in the past, you are being asked to share your insights and reflections. It is hoped that there will be some 'theological threads' that can be explored further, as a result of an interview with you. It is my intention that your

experience and reflection upon that experience, along with that of other people living with Hiv, will be central to my eventual written thesis.

2. If you agree, I would set up a suitable time for a conversation with you. I would expect the conversation to take between 60 and 90 mins maximum.

3. Unless you explicitly request otherwise, we will agree a pseudonym for you, that can be used in my writing, in order to ensure your anonymity. Similarly we will agree a suitable description of your situation (family background, job, nationality etc...) which you are happy to be used and will ensure an additional degree of confidentiality.

4. Should you agree, you may withdraw consent for any or all of the material gathered from conversation with you, to be used at any time, prior to actual publication as a short paper, article, or as part of my PhD Thesis.

5. The voice recording of any conversation will be kept by Vincent Manning alone. It will not be shared publicly, nor used more widely by any others, in any way as a voice recording.

6. General information relating to your participation will be with shared with members of St. Marys Research team, and a written, anonymised record of your participation will be kept for the purposes of PhD research and supervision.

Contact Details

Main researcher and contact details: Vincent Manning

vincentm@virginmedia.com T. 0207 7332440

Research supervisors: Dr. Peter Tyler tylerp@smuc.ac.uk T. 0208 2404000

Dr. Lynne Scholefield scholefl@smuc.ac.uk

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP TOGETHER WITH A COPY OF YOUR CONSENT FORM

Appendix 2.

St Mary's
University College
Twickenham
London



NAME OF PARTICIPANT: _____

Title of the project: What does it mean to be the 'Body of Christ living with Hiv/Aids'?

Main Researcher and contact details: Vincent Manning, 4 Thring House,
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Dr. Lynne Scholefield scholefl@smuc.ac.uk

Participants of the research:

1. I agree to take part in the above research. I have read the Participant Information Sheet which accompanies this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.
2. I understand that I am free to withdraw my participation from the research at any time, for any reason and without prejudice.
3. I have been informed that the confidentiality of the information I provide will be safeguarded
4. I am free to ask any questions at any time before and during the study.
5. I have been provided with a copy of this form and the relevant Participant Information Sheet.

Data Protection: I agree to the University College processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me.

Name of participant.....Signed.....Date.....

Name of
Researcher.....Signed.....Date.....

If you wish to withdraw from the research, please complete the form below and return to the main researcher named above. (Alternatively inform the main researcher by email, which will be acknowledged).

Title of Project:

What does it mean to be 'the Body of Christ' living with Hiv/Aids?

I WISH TO WITHDRAW FROM THIS STUDY

Name: _____

Signed: _____ Date: _____

Appendix 3.

INTERVIEW QUESTIONS - THEOLOGAINS

I am talking with you, because of your interest and awareness of Hiv and Aids over the past three decades. My research question concerns the significance of the phrase, 'the body of Christ living with Hiv'. This interview is being recorded, and I am grateful that you have agreed that I may use insights gained, to further this research.

Identifying key issues

1. What for you are the key theological issues that Hiv raises?
2. Kenneth leech has referred to Hiv and Aids as 'opening a pandora's box of unfinished business...' What do you think he might mean by this?
3. Can you identify any particular ways in which Hiv has changed you over the years – in terms of your own faith and theological outlook?

Hiv in the UK

1. In my research, I am focusing on the situation in the UK. What thoughts do you have in regard to the way in which the Church here has responded?
2. Are there aspects of Hiv in a western context that have particular significance?
3. What does the phrase 'the body of Christ living with Hiv' mean to you?

Theological Literature

1. In terms of the literature on Hiv, what writing stays with you, and why?
2. In terms of your own writing – what are you most proud of, and upon reflection, is there anything would you add or change to what you have written?
3. A fair amount has been written about Hiv – and that includes a fair amount of theology. Where are the gaps? What still needs to be explored in your opinion?

Concluding

Is there anything that you would like to add in these last few minutes?

If I was to turn off this recorder now, and promise not to quote you, are there other thoughts that you would be willing to share – 'off the record' as it were, that might help me in my research?

Appendix 4.

INTERVIEW QUESTIONS – PLWH

1. Basic / Background

- What pseudonym would you like me to use?
- What is your Age?
- Ethnicity and Country of birth?
- Marital status?

- Please will you describe your living situation?

Prompts: place of residence / relationships / family / employment

- When were you baptised?

2. Medical HIV Specific

- What was the date of your diagnosis?
- How often do you receive medical care?
- Are you currently taking any medications?
- How would you describe your current state of health?

3. Exploring feelings re faith prior to diagnosis

- How would you describe your faith, before your diagnosis?

Prompts: How did your faith affect you before your diagnosis?

Did you attend church?

Were you raised in a Christian household?

What did you believe most strongly?

Did your faith inform the choices you made in life?

Do you have a memory or story that has stayed with you that relates to an experience of faith before your diagnosis?

4. Exploring the experience of an Hiv diagnosis.

- How did you first learn of your HIV positive status?
- Can you describe how you reacted to your HIV diagnosis?

Prompts: What were your thoughts and feelings?

What did you do?

Did you tell anyone else? Why / why not? What reactions did you get from others?

- Did the news of your diagnosis cause any reaction in you at the time, that you would describe as relating to faith?
- If so, can you describe your thoughts and feelings at the time?

5. Has living with Hiv affected you in terms of your faith since the time of your diagnosis?

6. If so, can you describe how your faith has been affected?

Prompts: Has your understanding of Church teaching changed?

Has the 'practice' of your faith changed?

Has your understanding of God, yourself, or others changed?

7. Do you have anything else that you would like to say?

Prompts: Is there any strongly held 'belief or opinion' that you would like to share?

Are you able to summarise the main ways in which living with Hiv has impacted your faith?

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